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Mental capacity assessment for terminally ill adults requesting physician assisted suicide
A qualitative study using a grounded theory approach

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Mental capacity assessment for terminally ill adults requesting
physician assisted suicide: A qualitative study using a grounded
theory approach

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Thesis submitted in fulfilment of the requirements of the degree of

Doctor of Philosophy

Institute of Psychiatry

King's College London

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I dedicate this piece of work to my darling children, Penelope and Alfred; to Stephen; and also to one of my participants who sadly passed away recently. It was a great honour to have spent time with such a thoughtful, warm doctor-her patients were very lucky to have her.

Abstract

This thesis explores the issue of mental capacity assessment for terminally ill adults requesting physician assisted suicide. A grounded theory approach was used to explore the perspectives of senior doctors on assessment of mental capacity for this group. Twenty four doctors (nine psychiatrists, eight general practitioners, two oncologists, two palliative physicians and three surgeons) were theoretically sampled and participated in individual in depth interviews.

Constant comparative analysis of the data led to the emergence of the core category of *knowing the patient*. Knowing and the process of *getting to know* were individually interpreted and depended on the doctor, the patient and their intersubjective relationship. The process of getting to know comprised three elements: *temporality*, *dimensionality* and *quality* leading to a *sense of knowing*. *Contextualised knowing*, the sense of knowing informed by individualised contextual factors existed on a spectrum ranging from *not knowing* to *knowing too well*. The place of the specific doctor patient relationship on this spectrum related to the way assessment might be approached based upon *valued objectivity* whereby an 'objective' assessment was valued above a 'subjective' judgement. To preserve valued objectivity the approach to assessment varied according to how well the patient was *known*. If a patient was not known or not known well, a *structured/procedural approach* was favoured; for patients who were *known* there was a tendency toward a *gut feeling based approach*; but when a patient was *known too well* there was a perceived *threat to valued objectivity*, then a conscious return to a procedural, structured approach was favoured in order to return the sense of objectivity to the assessment process.

Comparison of these findings with those from other studies extended the model by incorporating wider contextual and temporal conditions of variation from which parallels with extant theory on the development of expert practice were drawn.

Referencing and language used in the text

The Harvard referencing system is used throughout the text.

Throughout this thesis I will describe the practice to which this study refers as **physician assisted suicide** as distinguished from the other practices in which life is ended upon request by a doctor such as voluntary active euthanasia, and non-physician assisted suicide (e.g. suicide assisted by a family member).

Physician assisted suicide is the act whereby a doctor provides a person with assistance to end their life at their request usually by prescribing lethal medication.

Physician assisted suicide has also been described using other terms such as 'assisted dying' or 'death with dignity' but I have chosen not to use these terms because they may also refer to or be conflated with other end of life care approaches-such as palliative care- which do not have the intention of ending life. Although the term physician assisted suicide has been criticised for its potentially stigmatising connotations, I have chosen to use this term for precision.

The term 'senior doctors' refers to doctors on the General Medical Council specialist register or general practice register working at 'consultant' level.

Quotations in the text are labelled with the participants' 1) geographical location e.g. Wales (Wales) North of England (NE) or South of England (SE); 2) professional group e.g. General Practitioner (GP) psychiatrist (Psych) or other doctor (Doc) and 3) identifying number e.g. _1. Therefore the first psychiatrist interviewed in the south east England group would be denoted as SEPsych_1.

1 Introduction

The ongoing debate on the legalisation of physician assisted suicide for terminally ill adults in England and Wales is both controversial and divisive. Over the past decade several attempts have been made to legalise physician assisted suicide for this group. As this thesis reaches completion, a new Assisted Dying Bill (Lord Falconer of Thoraton, 2014-2015) proceeds through the debate stages in the House of Lords and may, if successful, be presented to Parliament for consideration in 2015.

Integral to proposed assisted suicide legislation in England and Wales and Scotland, and in jurisdictions where assisted suicide is already legalised, is the stipulation that the person has the mental capacity to make the decision to request assisted suicide. This is intended as a key safeguard to protect the vulnerable from accessing assisted suicide inappropriately.

Despite the emphasis on mental capacity determination as a central safeguard in the process of assessing an adult requesting physician assisted suicide, little research has been done on the process of the assessment of mental capacity for this group.

This thesis will therefore explore, using qualitative methods and specifically a grounded theory approach, mental capacity determination as a safeguard in proposed legislation to allow terminally ill adults to end their lives by physician assisted suicide.

1.1 Identifying the problem

The main study forming the basis of this thesis was originally conceived as part of a wider project examining UK doctors' attitudes to voluntary euthanasia and physician assisted suicide following the defeat in the House of Lords of the Assisted Dying for the Terminally Ill Bill 2005. At that time there had not been a methodologically robust survey of UK doctors' attitudes to legalisation of these practices and the factors associated with these views, although representative surveys of a number of professional groups had been published with a range of response rates and shown variable levels of support e.g. (Dickinson et al., 2002, Pasterfield,

2006, Clark et al., 2001). At that time there had only been one survey of psychiatrists showing divided views on a change in the law (Shah et al., 1998).

Research Ethics Committee approval for a study of UK doctors' views on the legalisation of assisted suicide was initially granted on 3rd July 2006 by the National Research Ethics Service (NRES) by the NRES Committee London-Camberwell St Giles Group (formerly The Joint South London and Maudsley and Institute of Psychiatry Research Ethics Committee), NRES number 06/Q0706/36.

The Committee initially approved two studies,

- 1) A postal survey of UK senior doctors' opinions on the legalisation of assisted suicide and voluntary euthanasia (the findings of which are presented in chapter five)
- 2) A more in depth study of psychiatrists in the sample who identified themselves as willing to participate on return of their questionnaires from part one.

The initial intention for the second part of the study was to further investigate psychiatrists' attitudes to assisted dying practices, in particular exploring in detail how psychiatrists would go about assessing mental capacity for a person requesting physician assisted suicide. Mental capacity to make an informed decision had been incorporated as a proposed safeguard in the previous Bills presented to the House of Lords, and psychiatrists had been proposed as the professional group best placed to provide a second opinion should capacity be in doubt. No study however had examined how psychiatrists conceptualise capacity under this circumstance or explored in depth how capacity might be assessed clinically.

From the initial idea of a study examining psychiatrists' perspectives on mental capacity assessment for assisted suicide, the idea for the current study was developed in 2007, the same year that the Mental Capacity Act 2005 came into force; a year after Lord Joffe's third Bill to legalise physician assisted suicide (the Assisted Dying for the Terminally Ill Bill) had been defeated in the House of Lords; and ten years after the Oregon Death With Dignity Act (an Act to allow terminally ill Oregonians to end their lives by physician assisted suicide) was enacted.

At that time I was a trainee psychiatrist acquainted with the principles of capacity assessment, developing a familiarity with assessment of mental capacity in a variety of situations e.g. capacity to refuse or make decisions about treatment, or capacity to decide on place of care. I was fortunate to have had some experience of a research environment where detailed work on mental capacity determination was being conducted and issues around assessment of capacity for physician assisted suicide were frequently discussed. In the process of conducting the survey of doctors' attitudes to the legalisation of assisted suicide¹ (Lee et al., 2009) I had become familiar with the research literature on physician assisted suicide and the deliberations of the then recently concluded Select Committee on the Assisted Dying for the Terminally Ill Bill (House of Lords, 2005). I had also been introduced to palliative care psychiatry at St Christopher's Hospice², where I would later go on to work clinically and conduct research within a post part funded by the hospice. Given the combination of these interests and experiences, the ethical and clinical challenges of determination of mental capacity for physician assisted suicide were intriguing.

Although the original proposal for the project was to explore the attitudes of psychiatrists, an initial literature search (presented in chapter 2) pointed to a question of how not just psychiatrists, but doctors more widely, approach assessment of mental capacity for physician assisted suicide. The international data indicated that in jurisdictions where physician assisted suicide was legal, psychiatrists were assessing the capacity of only a small proportion of those patients accessing assisted suicide. There was very little written about capacity assessment for physician assisted suicide from the point of view of non-psychiatrists, and no examination of the interface between physicians and psychiatrists in the assessment process.

¹ See Appendix 12: Published papers

² St Christopher's Hospice is a large hospice serving a population of over a million people across five boroughs in South East London

This project began therefore with the question of how doctors, including psychiatrists would go about determining capacity for terminally adults requesting physician assisted suicide were the practice legal in England and Wales.

1.2 Study Aims

This study was designed and carried out with two broad aims:

1. To explore the perspectives of senior doctors on the process and practice of mental capacity assessment for terminally ill adults requesting physician assisted suicide were this practice to become legal in England and Wales.
2. To contribute to the ongoing debate on the proposed legalisation of physician assisted suicide in England and Wales by advancing what is known about an important but under-researched aspect of the proposed process: the assessment of mental capacity.

1.3 Using a grounded theory approach

The grounded theory approach originally described by Glaser and Strauss (Glaser and Strauss, 1967) is a qualitative methodology that seeks to view the world from the participants' perspective. The approach is primarily inductive, with themes emerging from the data rather than using a deductive approach based on hypothesis testing. For this reason a grounded theory approach is often used in situations where little is known about a topic.

In this study, a grounded theory approach was used to explore the perspectives of senior doctors on the assessment of mental capacity for terminally ill adults requesting physician assisted suicide.

A distinctive feature of the grounded theory approach is the conscious progression beyond the descriptive and toward theory development. This thesis therefore aimed to develop a grounded theoretical model that helps to explain variation in approaches to the situation in order to develop a better understanding of how mental capacity might be assessed in practice.

1.4 Thesis structure

This thesis is structured according to the conventions of a qualitative research report but also takes into account the specific conventions of grounded theory methodology. In particular, a review of the literature pertinent to the findings of the research is presented *after* the main body of results. The following sections present an overview of the chapters in this thesis.

1.4.1 Chapter 2: The research context

This chapter sets the scene for the research. It provides key definitions, outlines the legal status of physician assisted suicide worldwide and describes trends in uptake of assisted suicide and euthanasia. It shows the development of the legal landscape in England and Wales and presents the Bills currently proceeding through the legislative process in England and Wales and Scotland. It then presents in detail the Mental Capacity Act 2005 and relevant literature concerning the assessment of mental capacity, along with models of mental capacity in clinical practice. The chapter then moves onto considering the determination of mental capacity in jurisdictions where the practice is legal, with a focus on Oregon; and finally looks at proposed models for assessment of mental capacity for adults requesting assisted suicide.

1.4.2 Chapter 3: Methodology and methods

This chapter presents a consideration of the grounded theory methodology that underpins this thesis and the methods that were used in carrying out the study. The chapter begins with an explanation of the grounded theory approach as the most appropriate methodology to explore the research question. It then considers in detail the various approaches to grounded theory methodology and presents a rationale for the specific approach used. It then details the grounded theory approach used in this study and the methods employed throughout the study, with examples and illustrations of how these methods were used. The chapter also sets out the criteria used for evaluating rigour and how it was proposed that these standards would be achieved.

1.4.3 Chapter 4: Findings: ‘Contextualised knowing’ in assessment of mental capacity for terminally ill people requesting assisted suicide

This chapter presents the main empirical findings contributing to the thesis. The findings are based on analysis of 24 interviews with senior doctors in England and Wales exploring their perspectives on assessment of capacity for terminally ill adults requesting physician assisted suicide. The theoretical model emerging from analysis of the data centres on the ‘core’ concept of ‘knowing the patient’. How the patient is known was found to be influenced by a range of contextual factors for both the doctor and their patient. The ‘sense of knowing’ arrived at by a process of ‘getting to know’ was found to impact predictably upon the doctors’ proposed approaches to assessment of capacity, therefore explaining much of the variation in the data leading to the emergence of a theoretical model demonstrating the relationship between knowing and approach to decision making.

1.4.4 Chapter 5: Situating the findings within other sources of knowledge: comparing perspectives

This chapter situates the main empirical findings within other sources of knowledge concerning attitudes to and practice of physician assisted suicide for the terminally ill. The chapter first presents the results of a large survey of UK doctors’ attitudes to legalisation of physician assisted suicide, their perspectives on rational suicide and self-reported influences on their views on physician assisted suicide. Next the findings of a qualitative analysis of the expert submissions to the Commission on Assisted Dying are presented, particularly focusing on approaches to mental capacity assessment and conceptualisation of mental capacity. Following this, the chapter presents in detail the findings of a qualitative analysis of interviews with individuals involved in assessment of capacity for physician assisted suicide in the US state of Oregon, where the practice has been legal for nearly two decades. Finally an analysis of the House of Lords 2013 Second Reading debate on the Assisted Dying Bill is presented. The chapter concludes with a discussion of the main findings presented in chapter 4 in comparison to the findings of the studies presented in chapter 5.

1.4.5 Chapter 6: Linking emerging concepts with the extant literature: knowing and decision making in healthcare contexts

The core category 'knowing the patient' led to the emergence of the concept of contextualised knowing and a theoretical model of the relationship between knowing and decision making in assessment of mental capacity for terminally ill adults requesting physician assisted suicide. This chapter links these emerging concepts with the extant literature on knowing and decision making in healthcare contexts.

1.4.6 Chapter 7: Discussion

This chapter summarises and unifies the separate elements presented in the preceding chapters to present an explanatory model grounded in the data but taking account of other research findings and theoretical frameworks. This chapter also reflects upon the research process, methodological rigour and the strengths and limitation of the study. The chapter then discusses the implications of the research findings, makes recommendations based on these implications, and finally proposes future research directions.

2 The Research Context

In this chapter I will outline the legal and clinical contexts within which this study was conducted. Physician assisted suicide for the terminally ill is a practice which has been legalised or decriminalised in a number of jurisdictions over the past two decades. At this time the practice remains illegal in England and Wales under section 2 of the Suicide Act 1961, although a new Assisted Dying Bill (Lord Falconer of Thoraton, 2014-2015) has recently been presented to the House of Lords seeking to legalise physician assisted suicide for adults with a terminal illness in the final six months of life.

In this chapter I will firstly look at the ways in which physician assisted suicide is described and defined, then outline the legal status of this practice internationally and describe the rapid development of the legal landscape relating to assisted suicide in England and Wales across the duration of this project. I will outline the two Bills currently active in the UK-The Assisted Dying Bill 2014 (England and Wales) and the Assisted Suicide (Scotland) Bill 2013-2014 (MacDonald, 2013).

Secondly, I will define mental capacity, the determination of which is construed as a key safeguard in existing and proposed assisted suicide legislation and outline the contexts in which mental capacity is assessed. I will then outline the Mental Capacity Act 2005 (OPSI, 2005) (the piece of legislation upon which mental capacity determination in England and Wales is based), and then describe how mental capacity is determined in clinical practice.

Thirdly I will examine the interface between mental capacity and physician assisted suicide, focusing on Oregon, upon whose legislation the Assisted Dying Bill has been closely modelled. .

Lastly I will outline the current debates around mental capacity as a safeguard in the practice of physician assisted suicide and proposed models of mental capacity assessment for adults requesting physician assisted suicide.

2.1 Physician assisted suicide

Assisted suicide is the act whereby a person ends their own life with the assistance of another person. This assistance could take a variety of forms including providing a person with the means to end their life, taking them to a place where they are able to end their own life or otherwise assisting them in the process or act of ending their life, although the final act is done by the person themselves.

Physician assisted suicide is the act whereby a doctor provides a person with assistance to end their life at their request. In jurisdictions where this practice is legal, this assistance is given mainly to adults with terminal illness, although in some jurisdictions those with chronic physical disease or intractable mental disorders can also end their life in this way. The assistance provided by the physician (after a decision is made that the person is eligible according to legal criteria) is usually given in the form of a prescription for and provision of a lethal dose of the barbiturate medication pentobarbital, which is taken by the person by a means that they can manage, usually orally. This medication causes deep sedation, and death subsequently occurs due to respiratory arrest and typically occurs between a few minutes and several hours following ingestion.

Physician assisted suicide is one practice described under the broader umbrella of 'assisted dying', which also includes euthanasia, whereby a doctor administers a lethal dose of medication to a person. Euthanasia practice comprises 'voluntary euthanasia' in which a person deemed to be mentally competent is administered this medication and 'involuntary euthanasia' whereby a person deemed to be mentally incompetent is administered this medication. Euthanasia is legal in a number of jurisdictions, sometimes in parallel with assisted suicide, for instance in Belgium and the Netherlands. The key difference between euthanasia and physician assisted suicide is in who administers the medication. To be defined as physician assisted suicide the person must make take the final act of administering the medication himself.

2.1.1 The legal status of physician assisted suicide worldwide

Physician assisted suicide is currently practised legally in several jurisdictions including Oregon, Washington and Vermont in the US; Belgium, Luxembourg and the Netherlands in Europe; and is not a criminal offence in Switzerland (Bosshard et al., 2008).

Assisted suicide was briefly legalised in the Northern Territory of Australia in 1995 before being overturned in 1997 by the Federal Government. This Act has been the only one to have a requirement for mandatory psychiatric assessment. Assisted suicide is also technically permissible in Germany and the US state of Montana although not practiced officially in either jurisdiction.

2.1.1.1 Oregon, United States

Oregon was the first US state to legalise physician assisted suicide with the 1994 Death With Dignity Act (DWDA) (Department of Human Services, 1994), followed by Washington (Death with Dignity Act 2008) and Vermont (Patient Choice and Control at the end of Life Act 2013). The Washington and Vermont laws are almost identical to the Oregon Law.

The Oregon DWDA permits the provision of a doctor's prescription for lethal medication to be self-administered by an adult. The adult must have a terminal disease, defined as 'an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgement, produce death within six months'. There is no further requirement relating to the experience of suffering. The law applies only to those over 18.

2.1.2 Trends in uptake of assisted suicide and euthanasia

A recent systematic review analysed the available data to examine trends in uptake of euthanasia and physician assisted suicide (referred to as assisted dying) in several jurisdictions where the practice is legalised (Steck et al., 2013).

The authors reported deaths by assisted suicide as a proportion of all deaths by year. Twenty five studies were included comprising case series, surveys of physicians and studies reviewing death certificates. For countries where both euthanasia and assisted suicide are legal these

data were combined. Available data was variable in quality and countries varied in reporting practices.

The Netherlands showed the highest rates (between 1-3% of all deaths annually) followed by Belgium, Luxembourg (all with euthanasia and assisted suicide), Switzerland, Oregon and Washington (around 0.25%). This is also the temporal order in which the countries have legalised these practices. Rates increased over time in jurisdictions where there was more than one set of data to compare. In Oregon the rate increased from 0.05% of all deaths in 1998 to 0.23% in 2011. Across the jurisdictions, most people dying in this way were married followed by widowed and divorced. The proportions were mainly higher in men and those with higher educational level, and the most common age range was between 60-85 years. Cancer was the most common diagnosis in most studies, although in Oregon the highest percentage of physician assisted suicide was for patients with Amyotrophic Lateral Sclerosis, a degenerative neurological condition.

There is no official reporting requirement for assisted suicide in Switzerland but it is thought that around 180 British nationals have completed assisted suicide through Dignitas, the largest assisted suicide organisation, in the past ten years (BBC News, 2012).

2.2 Assisted suicide in England and Wales: Development of the legal landscape

Until 1961 suicide was illegal in England and Wales with those found guilty of attempted suicide liable to a fine or even imprisonment (BBC News, 2011). The Suicide Act (1961) amended the law in England and Wales related to suicide such that it was no longer considered a crime. Complicity in another person's suicide remained illegal however, according to section two of the Act:

A person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be liable on conviction on indictment to imprisonment for a term not exceeding fourteen years

Three unsuccessful attempts have been made in the past decade by human rights lawyer Lord Joffe to change the law to allow physician assisted suicide for terminally ill adults with the Patient (assisted dying) Bill 2003, and the Assisted Dying for the Terminally Ill Bill in 2004 and

2005. Under the terms of the Assisted Dying Bills, it would have become legal for doctors to prescribe a lethal dose of medication to adults who requested it, if the adult was diagnosed with a terminal illness, considered to be suffering unbearably, and did not lack mental capacity to make the decision.

This study was conceived in 2007, a year after Lord Joffe's third Bill to legalise physician assisted suicide (the Assisted Dying for the Terminally Ill Bill 2005) had been defeated in the House of Lords in 2006 and the same year that the Mental Capacity Act 2005 came into force. Around that time a number of surveys of the general public had been conducted which found general population support for physician assisted suicide to be at around 70-80% (MORI, 1987, NOP, 2004, YouGov, 2006). Assisting suicide remained illegal however, with those found guilty facing the possibility of up to 14 years imprisonment, although nobody had been handed down such a term.

Following a legal challenge in 2009 by Debbie Purdy (a campaigner for the legalisation of physician assisted suicide who has a diagnosis of multiple sclerosis) to the lack of clarity around factors to be considered in deciding whether to prosecute those who assist suicide, the House of Lords ordered the Director of Public Prosecutions (DPP) to issue a policy detailing factors in favour of and against prosecution. These guidelines were published in February 2010 (Director of Public Prosecutions, 2010). Factors in favour of prosecution included the 'victim' lacking mental capacity to make an informed decision and the person assisting the suicide acting in their capacity as a medical professional. Factors against prosecution included the victim being considered to have reached a 'voluntary, clear, settled and informed decision' to end their own life.

In September 2010, the "Commission on Assisted Dying" was convened, hosted by DEMOS (a think-tank focussed on power and politics), funded by author Sir Terry Pratchett and businessman Bernard Lewis and chaired by Lord Falconer. Its stated aims were to consider whether the current legal and policy approach to assisted dying in England and Wales was 'fit for purpose' and to,

...explore the question of what a framework for assisted dying might look like, if such a system were to be implemented in the UK, and what approach to assisted dying might be most acceptable to health and social care professionals and to the general public (DEMOS, 2010)

After gathering evidence, the Commission published its findings in early 2012 entitled 'The current legal status of physician assisted suicide is inadequate and incoherent' (DEMOS, 2012) and recommended the provision of the choice of 'physician assisted dying' for mentally competent adults with terminal illness. It criticised the current legal situation whereby adults can either travel to Switzerland to access physician assisted suicide through the organisation Dignitas or choose to end their lives by suicide in the UK with those assisting them facing the possibility of prosecution under the Suicide Act 1961.

The Commission proposed eligibility criteria to be met in order to proceed with a request for assisted dying. These comprised (i) the presence of terminal illness; (ii) that the decision should be voluntary; and (iii) that "(t)he person has the mental capacity to make a voluntary and informed choice, and the person's decision making is not significantly impaired as a result of mental health problems such as depression".

In autumn 2012 a new draft Bill '*Safeguarding Choice: A Draft Assisted Dying Bill for Consultation*' was published (Choice at the End of Life All Party Parliamentary Group, 2012), and in May 2013 a new Assisted Dying Bill was tabled in the House of Lords by Lord Falconer (2013a). The Bill was retabled in the House on 5th June 2014, and a lengthy debate leading to a Second Reading took place on July 18th, which led the Bill through to Committee stage for further detailed scrutiny on 7th November 2014. So far that committee debate has led to an amendment whereby there would be mandatory judicial review for every request.

On 25th June 2014 the UK Supreme Court handed down a judgement on three appeal cases: 1) Nicklinson and another vs the Ministry of Justice, 2) The Director of Public Prosecutions vs AM and 3) AM vs The Director of Public Prosecutions (United Kingdom Supreme Court, 2014).

These cases concerned two adults who wished to end their lives but were unable to due to their physical impairments. One of the key issues in the judgement was whether the current

law relating to assisted suicide is compatible with the human right to a private and family life (article 8 of the European Convention on Human Rights) and whether those who are unable, because of their disability, to end their own lives should therefore be given assistance to do so. The Court held that the question of whether the current law on assisted suicide is incompatible with Article 8 lies within 'the United Kingdom's margin of appreciation', but five of the nine Justices held that the Supreme Court has the constitutional authority to make a declaration that the prohibition on assisted suicide in Section 2 of the Suicide Act 1961 is incompatible with Article 8. Of those, three declined to grant a declaration of incompatibility but two would have done so. The question of whether to legalise assisted suicide was held to be one of a choice between two incompatible moral values: the sanctity of life and the principle of autonomy, thereby requiring resolution by means of a collective moral and societal judgement. Four of the Justices concluded that the question involves a consideration of issues that Parliament is 'better qualified than courts to assess' and that this assessment through Parliamentary process should be respected. They did, however say that if Parliament did not consider the matter, they would be prepared to revisit the issue of whether to grant a declaration of incompatibility, thereby potentially triggering a constitutional crisis.

2.3 Assisted Dying Bill 2014 (England and Wales)

The latest Assisted Dying Bill (Lord Falconer of Thoraton, 2014-2015) has been drawn up with the intent to 'Enable competent adults who are terminally ill to be provided at their request with specified assistance to end their own life; and for connected purposes' and is unchanged from the Assisted Dying Bill tabled in 2013 which was not debated as the session ended before this was possible.

According to the Bill, terminally ill adults will be able to receive physician assistance to end their own life. They must be assessed by two doctors (an attending doctor and an independent doctor) who certify that the person:

- i) Is terminally ill (has a life expectancy of 6 months or less)
- ii) Has the capacity to make the decision to end their own life

- iii) Has a clear and settled intention to end their own life which has been reached voluntarily, on an informed basis and without coercion or duress

Key differences between the Assisted Dying Bill (2013 and 2014) and the previous unsuccessful Bills tabled by Lord Joffe are:

- i) There is no longer a requirement that the adult requesting assisted suicide be suffering (there was a condition in the previous Bill that the person be 'suffering unbearably').
- ii) There is no longer a requirement that the person **must** be referred for a psychiatric assessment should capacity be in doubt.

Mental capacity is proposed as a key safeguard to protect vulnerable people (e.g. those with depression impairing their decision making ability) from inappropriately accessing physician assisted suicide. The Bill stipulates that the Secretary of State *may* issue one or more codes of practice in connection with 'assessing whether someone has the capacity to make such a decision' and 'recognising and taking account of the effects of depression or other psychological disorders that may impair a person's decision-making'. Mental capacity in this Bill is construed in accordance with the Mental Capacity Act (OPSI, 2005). The Bill is broadly similar in content and scope to the Oregon Death with Dignity Act 1994 as with previous Bills presented to the House of Lords.

2.4 Assisted Suicide (Scotland) Bill 2013-2014

In parallel with the Assisted Dying Bill, Scotland's most recent Bill to legalise physician assisted suicide (MacDonald, 2013) was introduced to Scottish Parliament on 13th November 2013. Originally introduced by MSP Margo McDonald who recently died, the 'member in charge' is now MSP Patrick Harvie.

The Bill proposes an Act of Scottish Parliament to 'make it lawful in certain circumstances to assist another to commit suicide'. Like the Assisted Dying Bill it makes provision for those with terminal illness but also 'life shortening' illness, thus making the prognostic conditions less well defined. It also specifies that the Bill only applies to those who have capacity to make the decision. According to section 12 of the Bill a person has the capacity to make a request if they

are 'not suffering with a mental disorder...which might affect the making of the request and is capable of i) making the decision to make the request ii) communicating the decision iii) understanding the decision and iv) retaining the memory of the decision, 'in line with the Adults with Incapacity (Scotland) Act 2000, adapted to relate specifically to the context of making requests under the Bill'. According to the Code of Practice (2008a), Section 12 does not require specialist assessment of capacity by a psychiatrist because,

...assessment of capacity is not generally something which requires psychiatric expertise, in the absence of any reason to suspect that the person has any form of mental disorder.

However the guidelines do recommend that the practitioner dealing with the first or second request, seek any specialist input they feel is needed to inform their assessment.

A key departure from the Assisted Dying Bill (England and Wales) is the requirement that the person make a witnessed 'preliminary declaration' that will be recorded in their medical notes prior to making their first formal request for assisted suicide. Two formal requests are then required 14 days apart in order to proceed. Detailed medical statements by two doctors endorsing the request must be made by two doctors following the first request in order for the process to proceed. Any 'act of suicide (or attempted suicide)' must then be made within 14 days of the second request.

The Bill was debated in Scottish Parliament during the 2014/2015 session and fell during the stage one debate in May 2015.

2.5 Mental Capacity

Mental capacity is a legal, clinical and social construct (Hotopf, 2005). In a legal context mental capacity is a person's 'ability to do something, including making a decision, which may have legal consequences for that person or other people' (The British Medical Association and the Law Society, 2010). In England and Wales, mental capacity is determined using the framework of the Mental Capacity Act 2005 (OPSI, 2005).

2.5.1 Principles of mental capacity

Personal autonomy is the key principle that has governed the development of the legal concept of mental capacity and its clinical application. Jurisdictions with mental capacity legislation e.g. the Mental Capacity Act 2005 in England and Wales, base this legislation on the principle that adults have a right to self-determination and their autonomy should be respected by obtaining their consent; and if this autonomy is to be overridden it should be on the basis that the person lacks the capacity to make an autonomous decision about the situation in question.

2.5.2 The Mental Capacity Act 2005

The Mental Capacity Act 2005 (MCA), which came into force in 2007, is a codification of the previous common law principles of mental capacity drawn from case law.

It is an Act intended 'to make new provision relating to persons who lack capacity' and defines a lack of capacity as,

...if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or the brain.

The Act specifies that 'it does not matter whether the impairment or disturbance is permanent or temporary' and cannot be established based on the person's age, appearance, condition or behaviour (thus avoiding 'status based' capacity determination e.g. where a person is deemed to lack capacity simply because they have a learning disability or because they are elderly).

The Act covers decisions made on behalf of persons lacking capacity only if they are over the age of 16.

The Mental Capacity Act 2005 rests on five key principles,

- 1) A person must be assumed to have capacity unless it is established (on the balance of probabilities) that he lacks capacity
- 2) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success (a duty to optimise capacity)

- 3) A person is not to be treated as unable to make a decision merely because he makes an unwise decision (thus avoiding outcome based capacity determination, where the decision about whether the person lacks capacity is made on the basis of the decision rather than the process of arriving at that decision, in order to minimise the effect of paternalism)
- 4) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made in his *best interests*. This is not specifically defined but does specify aspects to be considered when determining best interests including ascertaining their present and past wishes and the beliefs and values that might have informed their decision making when they had capacity.
- 5) Before the act is done, or the decision made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of a person's rights and freedom of action.

The Act does not define 'mental capacity' but does define the conditions under which a person would be considered to lack capacity and this is determined using a two stage process.

Firstly there is a diagnostic threshold in which the person 'lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain'. If on assessment they do not have such an impairment or disturbance of functioning then they are free to act in any way they choose in relation to the matter.

If the first condition is satisfied then the person lacks capacity to make a decision for himself if he is unable:

- 1) To understand the information relevant to the decision
- 2) To retain that information (for long enough to use the information to make the decision)
- 3) To use or weigh that information as part of the process of making the decision, or
- 4) To communicate the decision (by whatever means possible)

In considering how mental capacity determination is construed in the Assisted Dying Bill, the key relevant principles are the first three as the Bill does not propose to allow physician assisted suicide for those lacking capacity in their 'best interests' and would only apply to 'capacitous' persons.

2.5.3 Assessment of mental capacity

Whilst the test of mental capacity is defined in law it is assessed mainly by clinicians and those involved in the social care of citizens e.g. social workers and the police, although there is no specification in the Mental Capacity Act 2005 as to who should appropriately assess capacity in different circumstances. Mental capacity determination is relevant across a number of medical and legal settings where a decision is being made that may be legally or medically accountable. Broadly, mental capacity is determined in practice according to the principles and procedures of the Mental Capacity Act but in some scenarios (e.g. capacity to execute a Will or capacity to testify in court), specific tests of capacity have been developed through case law.

To possess capacity to make a Will for example, based upon *Banks v Goodfellow* [1870] LR 5QB 549 the *testator* must 1) be aware that the wishes expressed in the Will take effect on death 2) understand the way the estate will be distributed amongst beneficiaries 3) have a recollection of the property that is being disposed of 4) understand the nature and extent of the claims on them and 5) know and approve of the contents of the Will at the time it was executed (Jacoby and Steer, 2007).

Examples of scenarios relevant to medical practice are capacity to consent to or refuse medical investigation or intervention, capacity to discharge oneself from hospital against medical advice or capacity to decide upon place of residence or care.

Whilst the dimensions of capacity exist on a continuum, determination of mental 'competence' is binary. Thresholds for competence are influenced by how much risk is incurred by the decision being made, with high risk decisions requiring 'greater' capacity or margin for error (Hotopf, 2005) as established in English Law by Lord Donaldson in the case of *Re T (Adult: Refusal of treatment)* (Great Britain, 1992). This view is controversial however as it

has been suggested that it opens the door for medical paternalism (Buchanan, 2004) and that risks are not judged consistently by clinicians (Kim et al., 2006, Cale, 1999, Wicclair, 1999).

The potential for a broad range of opinion in individual cases was exemplified by the debate surrounding the decisions made in the case of Kerrie Woollorton, a 26 year old woman who died in 2007 after drinking antifreeze and then refusing life-saving treatment having been determined to have capacity by the treating team (David et al., 2010).

Whilst, according to the Mental Capacity Act, the legal definition of (a lack of) capacity is precise, the application of the definition in clinical practice is less clear cut. Difficulties exist in assessing and operationalising how a patient uses and weighs information and how affective states impact on capacity (Hotopf et al., 2011a, Owen GS et al., 2013, Tan and Hope, 2006, Kim et al., 2011, Appelbaum, 1998). In considering the impact of mental disorder on mental capacity a recent systematic review showed that judgement of a lack of decision making capacity due to depression varied between studies according to the acuity of depressive illness and whether structured assessment tools were used (Hindmarch et al., 2013).

The Mental Capacity Act 2005 test of capacity only applies to England and Wales.

Internationally, most jurisdictions base their capacity laws on a 'functional' approach which is decision and time specific rather than 'outcome' or 'status' based approach and capacity is presumed; (Wong et al., 1999b) however, different jurisdictions use different components for capacity determination; for example in the US, the capacity test is based on national case law and evaluates the abilities of 'understanding', 'appreciation', 'reasoning' and 'expressing' a choice. Also, there are a number of instruments used to assess capacity (Vellinga et al., 2004, Sullivan, 2004) for example the widely used Macarthur Competency Assessment Tool (MacCAT-T) developed in the US and based on the US legal test of capacity (Appelbaum and Grisso, 1995). This tool has been shown to have good inter-rater reliability in a range of settings including psychiatric inpatient settings (Cairns et al., 2005, Grisso et al., 1997). A recent study comparing a medical to a psychiatric setting found that 'appreciation' was a

better determinant of decision making capacity in the psychiatric setting whilst 'reasoning' was a better determinant of this capacity in the medical setting (Owen et al., 2013)

The MacCAT-T and legal tests of capacity have been criticised by a number of authors for concentrating too closely on the cognitive (intellectual) aspects of capacity (Tan et al., 2006, Tan and Hope, 2006, Charland, 1998, Martin and Hickerson, 2011, Doorn, 2011). In her paper examining mental capacity using an anthropological approach, Doorn (Doorn, 2011) argues that the available literature focuses on criteria for the assessment of competence without elaborating on what it is to be competent or incompetent to make a decision. She describes 'thin' and 'thick' conceptualisations of capacity which correspond to a more cognitive conceptualisation based on 'negative' autonomy (self-determination with freedom from the interference from others) and a richer conceptualisation which acknowledges values (both of the patient and clinician) and is based on 'positive' autonomy (the potential for self-development and fulfilment). She argues that assessment tools used to measure capacity have their roots in a 'thin' conceptualisation which does not acknowledge the 'value ladenness' of capacity decisions but relies on narrower cognitive abilities. This view is not without criticism (Shah, 2011, Williamson, 2011) but is echoed by other authors who argue that a value neutral or value free conceptualisation of capacity is potentially problematic in practice (Owen G et al., 2009), that these areas may be open to influence by individual factors in both the patient and the assessing clinician(s) (Varghese and Kelly, 2001) and that capacity assessment is inherently normative and irreducible to a set of objective criteria (Banner, 2012, Juth and Lynoe, 2010), in line with many aspects of decision making in psychiatry (Fulford, 2005).

In their study examining the assessment of mental competence to consent to or refuse treatment for anorexia nervosa, Tan and colleagues (Tan et al., 2006) compared the MacCAT-T with semi-structured interviews to determine capacity and found that almost all of the sample of women with anorexia nervosa would be found to be mentally competent using the MacCAT-T whilst the competence of most to refuse treatment for their anorexia was questioned based on the interviews due to other factors that are not components of the MacCAT-T test of

capacity. Areas such as authenticity, stability and relativity of values were found to impact upon decision making for these patients. The authors argue that assessment of context, meaning and personal values are absent from standard tests of capacity, so cannot truly take into account the effects of mental disorders such as anorexia to impair decision making, meaning that that patients may be falsely judged to have capacity and therefore risk further diminution of their health and even death, without compulsory treatment. Tan and colleagues support the proposal of Charland (Charland, 1998) that the assessment of capacity should include assessment of the 'internal rationality' of the decision making process and that assessors should be asking 'why' as well as 'what'. They acknowledge that this is inherently value laden, in that the subject's rationale must be compared with a relative norm or the subject's premorbid values, in order to be assessed. Martin and Hickerson (Martin and Hickerson, 2011) likewise argue for an approach that encompasses a more complex view of the role of 'time, others and identity in constituting the capacity for individual autonomous judgement'. More fundamentally, the assessment of mental capacity has been criticised because of its basis in the concept of personal autonomy, itself a controversial construct which may be challenged in conditions such as addiction and anorexia nervosa (Freyenhagen, 2009, Ashley, 2011).

In clinical settings, requests for capacity determination have been critically examined and it has been suggested that capacity assessments are often triggered when the bioethical principles of beneficence and autonomy conflict (Kontos et al., 2013, Ranjith and Hotopf, 2004). Tan and colleagues also argue that the automatic assessment of capacity to consent to or refuse treatment for those with mental disorder may be discriminatory, as those without mental disorder refusing treatment may never have their capacity doubted but might fail a capacity test if it were applied (Tan et al., 2006).

Currently in England and Wales, mental capacity and mental health legislations are separate, with the Mental Health Act (1983) MHA (amended in 2007) used for the compulsory treatment of individuals with mental disorder. The determination of mental capacity is used within areas

of mental health legislation however, for example in consent to treatment for patients detained under the MHA. It is not always clear in complex situations whether the use of the MHA or MCA is most appropriate, although the MHA is usually recommended when there is uncertainty. It has also been shown in an observational study of assessments under the MHA that professionals' decisions take into account the decision making capacity of the patient in an attempt to avoid the 'hard paternalism' of detention under the MHA, favouring the 'soft paternalism' of detention due to incapacity, even though the MHA is enacted (Fistein and Fritz, 2014).

One proposed solution to these legal and clinical complexities is the introduction of a single piece of legislation to cover non-consensual treatment of both 'physical' and 'mental' illnesses (Dawson and Szmukler, 2006). In this paper the authors argue that there should be a 'comprehensive involuntary treatment statute' with determination of decision making capacity as the central criterion. They argue that this would reduce discrimination against those with mental disorder and provide a legal framework based on consistent ethical principles.

Mental capacity assessment is a challenging clinical area even for those considered to be 'experts' as shown in a survey of the Academy of Psychosomatic Medicine which found that members view assessment of decision making capacity as challenging and time consuming with a weak evidence base (Seyfried et al., 2013).

2.5.4 Post legislative scrutiny of the Mental Capacity Act 2005

On 13th March 2014, the House of Lords Select Committee on the Mental Capacity Act 2005 published a post legislative scrutiny report (Lords, 2014). The report followed an extensive information gathering exercise in which 61 witnesses were questioned over 15 public hearings and additionally, 206 written submissions were considered. The purpose of the scrutiny was to consider the legislation in practice and determine whether it was meeting the purpose for which it was designed.

The Committee noted enthusiastic support for the Act but was highly critical of the way that it has been implemented in clinical practice. They reported that the Act is poorly understood

amongst clinicians and that when assessments are carried out they often do not adhere to its key principles. A lack of understanding of the principle of presumption of capacity was identified, with clinicians presuming incapacity due to the condition of the patient or the patient having made an 'unwise' decision, or using the principle to justify neglect of vulnerable patients.

The report further highlighted a prevailing culture of paternalism and risk aversion which was identified as a barrier to the enabling ethos of the Act.

2.6 Models of mental capacity assessment in clinical practice

The majority of mental capacity assessments in clinical practice are triggered by either a refusal to agree to a proposed treatment or when it is unclear whether a patient is able to consent to a treatment being offered. Once an assessment is triggered, the assessment of capacity (according to the Mental Capacity Act 2005) focuses on determining whether the patient lacks capacity to make the decision in question.

There are currently few capacity assessments made in routine clinical practice which are akin in quality to a capacity assessment for physician assisted suicide and the Mental Capacity Act test of capacity does not easily map onto unsolicited requests for intervention. Two examples of such unsolicited requests would be for termination of pregnancy and for interventions intended to change bodily appearance or reassign gender.

The Royal College of Psychiatrists has produced Good Practice Guidelines for the Assessment and Treatment of Adults with Gender Dysphoria (Royal College of Psychiatrists, 2013), in which there is a presumption of competence to consent to assessment, and consideration of potentially treating adults who lack capacity in their best interests e.g. in case of learning disability. There is no guidance on how capacity should be assessed but the advice to presume capacity and the mention of 'best interests assessments' implies that the Mental Capacity Act is construed as the legal framework. Gender reassignment therefore potentially differs from physician assisted suicide in terms of capacity assessment in that decisions to undergo gender reassignment might be taken in the best interests of patients that lack the ability to make the

decision for themselves. Likewise the NHS England Interim Gender Dysphoria Protocol and Service Guideline (NHS England, 2013) cites 'Capacity to make a fully informed decision and to consent for treatment' for each of five proposed interventions but at no point defines this capacity or sets out how this capacity should be determined.

Howe (Howe, 2008) explores the ethical implications of capacity assessment and concludes that normative judgements are intrinsic to capacity determination. In his discussion of new contexts for capacity determination he introduces the subject of patients requesting novel surgeries giving the examples of vaginoplasty and amputation of healthy limbs (which he refers to as 'quality adjustment procedures'). There have been several cases of people self-amputating limbs because they felt unable to live with the suffering caused by the ongoing attachment to the limb and were unable to find a surgeon willing to agree to carry out the amputation e.g. (Sorene et al., 2006). He identifies capacity determination in these areas as particularly difficult but does not advance any solution to how to appropriately assess capacity to decide to undergo these procedures which would never ordinarily be proposed to the patient as potentially therapeutic, although the patient themselves may request them in order to relieve their suffering.

The British Medical Association guidance on the law and ethics of abortion (British Medical Association, 2007) considers capacity to consent to abortion according to the Mental Capacity Act 2005 and sets out the four step capacity test in this guidance. They also set out conditions in which the procedure could be performed in the best interests of a person without capacity to consent either temporarily or permanently. They advocate that judicial review of the decision may be required under some circumstances e.g. when the wishes of the family are in opposition to the decision of the medical team.

Again, this guidance does not translate to capacity to request assisted suicide which would not be undergone by a person lacking capacity. It seems that in England and Wales there is little to guide how these assessments should proceed, other than the very broad framework of the Mental Capacity Act 2005.

One solution proposed to this difficulty is, instead of differentiating between consent to treatment and request for treatment, make all healthcare interventions subject to a 'request for treatment' with Request for Treatment Forms or Patient Centred Consent Forms supplanting the more traditional Consent Forms. In his paper based on a 2010 Hunterian lecture, Shokrollahi (Shokrollahi, 2010) proposes this change in practice based on a need for a new process that fully embraces the modern medical ethos of patient autonomy and patient centred care by reversing the dynamic of the doctor proposing the intervention and the patient consenting to it. Here, what is proposed is that the patient requests the intervention from the doctor, is provided with information relating to the intervention, then uses the form to record in their own way, using their own writing, what they understand to be the risks and benefits of the procedure. There is then an opportunity to meet with the doctor to correct any misunderstandings and make clarifications, and once this has been done, the doctor then signs the form to say that they accept to undertake the procedure. According to Shokrollani, this process incorporates a 'soft' test of capacity because in order to negotiate the request process, the capacity to request the intervention is inherent. This process of 'Request for Treatment' has not reached mainstream surgical practice however, and is little discussed in subsequent literature concerning mental capacity assessment. This means of testing capacity also appears to rely on a mainly cognitive conceptualisation of capacity in which a sufficient understanding of the procedure and its alternatives would be all that was needed to be found capacitous.

2.7 Determination of mental capacity in jurisdictions where physician assisted suicide is permitted

No jurisdiction has a specific legal test for determining whether a decision to request physician assisted suicide is capacitous (McCormack and Flechais, 2012) although some have produced guidance to support capacity determination in this circumstance (e.g. the Oregon Death With Dignity Act 1994 Guidelines). None of the statutes require that a psychiatric assessment of capacity takes place as part of the overall process of assessment except in Belgium for patients who are not considered to be suffering from a terminal illness.

The two identical England and Wales Assisted Dying Bills recently tabled by Lord Falconer have been openly modelled on the 1994 Oregon Death With Dignity Act (DWDA), enacted in 1997, which has now been in force for 16 years (Department of Human Services, 1994). Because of this similarity, I will examine the situation in Oregon in detail. In the following section I will outline how the Oregon DWDA guidance addresses the issue of mental capacity and the empirical literature that supports these recommendations.

2.7.1.1 Determination of capacity according to the Oregon Death With Dignity Act 1994

According to the Oregon Death with Dignity Act (1994) statute a person is 'capable' if in the opinion of a court or in the opinion of the person's attending physician or consulting physician, psychiatrist or psychologist, they have the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the person's manner of communicating if those persons are available AND in addition that they are not suffering from a psychiatric or psychological disorder or depression causing impaired judgment.

Along with the Act, guidelines have been published intending to help clinicians to administer the Act (The Task Force to Improve the Care of Terminally-Ill Oregonians, 2008) and in addition, a report is published annually giving details of the number of prescriptions of lethal medication, the number of deaths, the reasons given by patients for choosing assisted suicide, the demographics of those dying, and any instances of failure to comply with the legal procedures or reporting practices (Oregon Health Authority).

The number of psychiatric evaluations as a proportion of the total number of deaths is published each year and is summarised in Table 1.

Table 1: Percentage of patients in Oregon receiving lethal medication who have had a psychiatric evaluation as part of the assessment process

Year	Percentage receiving a psychiatric evaluation
1998	27
1999	37
2000	19
2001	14
2002	13
2003	5
2004	5
2005	5
2006	4
2007	0
2008	3.3
2009	0
2010	1.5
2011	1.4
2012	2.6
2013	2.8
2014	2.9

It can be seen that in the early years after the DWDA was passed, psychiatric evaluation was fairly frequent but after 5 years of physician assisted suicide being legalised, psychiatric evaluation became more infrequent, and in some years no patients were evaluated. The numbers of psychiatric evaluations as a proportion of the number of requests are not published³. Also not published is the number of prescriptions given as a proportion of the number of patients requesting assisted suicide and what proportion of these requests were refused due to the patient being found to lack capacity.

Guidelines to accompany the Oregon DWDA were produced by the 'Taskforce to Improve the Care of Terminally Ill Oregonians' convened by the Center for Ethics in Healthcare at the Oregon Health and Science University in Portland (The Task Force to Improve the Care of Terminally-Ill Oregonians, 2008). The overall goal of the taskforce was to improve end of life care in Oregon, and it took a neutral stance on the new legislation in drafting the guidelines. The guidelines were first produced in 1998 but have since been revised four times, most recently in 2008. They were produced with the acknowledgement that 'in creating a new legal option for terminally ill patients, the Oregon Death with Dignity Act has added a new dimension to medical practice'. The guidelines cover a number of areas, including 'Meaning behind a request', 'Conscientious practice', 'Patient rights and responsibilities', 'The attending and consulting physician' and 'Mental health consultation'.

When discussing the meaning behind a request the guidelines address the 'complex question of motivation' and look not just at the person's motivations but those of the doctor and how those might impact on the person's decision making,

The patient's choices may involve an interactive set of factors that include the patient's religion, the doctor-patient relationship, perceptions of quality of life, and other psychosocial circumstances. A health care professional may be motivated by compassion for the patient, feelings about participating in the Oregon Death with Dignity Act, or moral and religious beliefs, when considering how to respond.

³ Figures requested but not supplied

The guidelines report the most common reasons for persons requesting assisted suicide are perceived loss of dignity, perceived loss of autonomy and the inability to participate in activities that make life enjoyable. Current pain and suffering are less common reasons for requesting assisted suicide among Oregonians. There is an explicit acknowledgement of the subjectivity in professionals' judgement on whether these factors constitute appropriate motivations for assisted suicide,

In addition to probing the patient's issues, the attending physician needs to contemplate his/her own motivations and beliefs. He/she will have emotional reactions and will need to consider the personal consequences of agreeing to provide a lethal dose of medication. The attending physician's beliefs about death and the meaning of pain and suffering are likely to impact how he/she interacts with patients and presents care options.

In considering the physician's role in assessing a patient requesting assisted suicide, the guidelines strongly recommend that physicians examine their own values before being confronted with a request, and 'consider these values in the context of relationships with colleagues, institutions, and organisations'. This is of particular pertinence when there might be a conflict between the values of the physician and that of their colleagues or institution.⁴

The guidance addresses the issue that some patients' face value requests for assisted suicide might be an attempt to communicate another need, particularly in the context of personality difficulties,

Patients may communicate one thing, yet mean quite another. Patients frequently visit physicians with a particular symptom yet have deeper worries that remain hidden. Eliciting hidden factors may promote healing and reduce suffering.

Examination of the meaning of the request is considered separately in the guidance however from the assessment of mental capacity to make the request, with exploration of meaning intended to occur early in the process as part of a comprehensive review of the needs of the patient at the end of life. This may include an exploration of the options available to them including better symptom management, enrolment in hospice care or addressing psychosocial difficulties and helping the patient to regain a sense of control toward the end of life.

⁴ In Oregon institutions may opt not to be involved in assisted suicide as well as individual practitioners

In their advice to attending and consulting physicians in determining ‘decision-making capacity’ for physician assisted suicide, the guidelines state that the person must be able to ‘understand the information provided (medical diagnosis, prognosis, potential risks associated with taking the medicine), weigh this information in the balance and communicate a choice’.

When considering mental capacity assessment in more detail and the impact on mental disorder on mental capacity, the guidelines emphasise a specific role for psychiatrists and psychologists within the DWDA and how physicians in any doubt about the patient’s decision making capacity should refer to a psychiatrist or psychologist for a more expert assessment. The guidelines acknowledge however that referrals for psychiatric assessment are infrequent as shown in Table 1, despite evidence showing that physicians do not feel confident in diagnosing depression in patients requesting assisted suicide (Lee et al., 1996) and the findings of a study in Oregon showing that one in four people requesting assisted suicide had a diagnosis of depression and three out of eighteen patients completing physician assisted suicide during the study period were assessed to have major depressive disorder (Ganzini et al., 2008), which may have impacted on mental capacity.

The Oregon guidelines define the mental health consultation as ‘a form of capacity or competence evaluation, specifically focused on capacity to make the decision to hasten death by self-administering a lethal dose of medication’.

The guidelines state that,

Mental health professionals’ views on the ethical permissibility of the Oregon Act are likely to influence the standards used in diagnosing a mental disorder and determining whether the mental disorder causes impaired judgment.

In 1997, 456 forensic psychiatrists in the US were surveyed about their views on evaluation of competence to consent to physician assisted suicide (Ganzini et al., 2000a). Twenty four percent believed that psychiatric participation in determining competence would be unethical, 3% believed that psychiatric evaluation was not necessary as a safeguard, and the remaining 61% thought that an evaluation of capacity should be required in some or all cases. Psychiatrists with ethical objections to physician assisted suicide recommended higher thresholds for competence

and a more extensive review of the decision. There was a lack of consensus about the processes and standards that should be used to determine competence for physician assisted suicide. The study found that the values of the respondents influenced their clinical-legal opinions about decision making capacity.

The credentials specified in the guidance identifying psychiatrists and psychologists as the most appropriate professionals to assess mental capacity for assisted suicide were:

...their expertise in diagnosing psychiatric disorders, examining mental status, and understanding irrational forces that influence decision making.

According to the guidelines, once mental disorder, significant cognitive impairment and evidence of coercion have been excluded, 'most patients will qualify for the Oregon Act'. They state that, 'Attending physicians are unlikely to refer patients that they know well' although knowing well is not further defined; and that patients are more likely to be referred for treatment of delirium or severe depression than for a capacity assessment.

A key area of difficulty in determination of capacity identified by the guidelines is what impact mental disorder has on decision making 'even by expert assessment'. They cite the findings of a survey of Oregon mental health professionals showing that 'only 6% of psychiatrists and psychologists were very confident that they could determine whether a mental disorder was influencing the judgment of a person requesting a prescription under the Oregon Act, if they only saw the patient once' (Lee et al., 1996).

Because of the difficulties identified in determining how mental disorder impacts on capacity, along with the evidence which shows that depression is common in terminally ill patients with a desire for hastened death (Breitbart et al., 2000, Chochinov et al., 1995, Price et al., 2011), the guidelines strongly recommend that patients requesting assisted suicide be screened for depression using validated depression tools and referred for specialist assessment if screening indicates depression. They also recommend that mental health professionals who recognise strong personal biases for or against physician assisted suicide should consider declining consultation as this is likely to have a bearing on their decision making.

2.7.2 Other published guidelines for determination of mental capacity for terminally ill adults requesting physician assisted suicide

Elsewhere in the US, attempts have been made to establish guidelines for assessing mental capacity for terminally ill adults requesting physician assisted suicide (Werth, 1999a, Werth et al., 2000). These proposed guidelines recommend thorough assessments of history, mental state and mental capacity; and administration of several assessment tools to aid the clinician in arriving at a decision. The MacCAT-T (Grisso et al., 1997) was endorsed as an instrument that may be appropriate for use in assessment of capacity as part of a wider information gathering process, although it was recommended that this be specifically validated for this purpose⁵.

These proposed guidelines were criticised by commentators who argued that they relied too heavily on checklists and formal tests and risk unnecessary bureaucratic intrusion (Youngner, 2000), that the guidelines provided false assurances of objectivity and rigour and did not acknowledge the subjectivity of decision making (Burt, 2000, Martyn and Bourguignon, 2000), and that they would primarily serve as a legal indemnity for doctors (Caplan et al., 2000).

Other published draft guidelines for assessment of patients requesting assisted suicide stress the importance of determining decision making capacity and assessing thoroughly for the presence of depressive illness, (Bascom and Tolle, 2002, Emanuel et al., 1998, Hudson et al., 2006), but give no further guidance on how this should be approached.

Guidelines have also been proposed to determine who is competent to determine mental capacity (Werth, 1999b) and outline the specific training and experience that would qualify clinicians to confidently undertake mental capacity assessments. The training suggested is lengthy, extensive and wide-ranging. These guidelines did not, however, address how this training would aid the clinician in the process of capacity assessment. They also appeared to assume that this training would qualify only a few clinicians to undertake this kind of work, and would be out of the scope of most clinicians' expertise.

⁵ A study validating the tool for this use does not appear to have been conducted, or at least not published.

2.8 Proposed models of mental capacity assessment for physician assisted suicide

The lack of a specific capacity test for assisted suicide has been questioned by Stewart et al (Stewart et al., 2010) who have proposed a specific test of capacity for physician assisted suicide based on analysis of recent cases. They take as their basis the test of competence to consent to medical treatment. This test, in accordance with the Mental Capacity Act is based on a presumption of competence and this competence must be disproved on the balance of probabilities. From this basis they then propose using the common law test of competence but meeting a standard of competence required for informed (as opposed to basic) consent. They further advise that the patient should be able to 'appreciate' the following: 1) His or her medical diagnosis 2) His or her prognosis 3) The potential risks of taking the medication to be prescribed 4) The probable result of taking the medication to be prescribed and 5) The feasible alternatives, including, but not limited to, comfort care, hospice care and pain control.

In acknowledgement of the potential influence of mental disorder on capacity they also advocate a 'cautious and rigorous examination of the effect of mental illness on the person's competence'. They also propose that the person be assessed as part of the test for the presence of 'undue influence' and that the decision should be consistent over time with past expressed wishes and beliefs. In developing the guidance however, the authors envisaged the test being applied retrospectively after a physician assisted suicide in conjunction with the DPP guidance on prosecution, even though the wording of the test suggests prospective application.

2.9 Summary

Physician assisted suicide is legal in a number of jurisdictions in Europe and the US and Bills to legalise physician assisted suicide are currently active in England and Wales and Scotland. These Bills are closely modelled on the 1994 Oregon Death With Dignity Act which has now been in force for 16 years.

One of the key proposed safeguards in the England and Wales Assisted Dying Bill 2014, as with previous unsuccessful Bills, is the determination of mental competence construed in accordance with the Mental Capacity Act 2005.

The Mental Capacity Act is intended to allow those with decisional autonomy the freedom to make a decision for themselves and for those without decisional autonomy to have a decision made on their behalf in their 'best interests'. The Act is based on principles that intend to make capacity determination a 'functional' test based on the process of decision making rather than the outcome of the decision or the status of the person making the decision, in order to reduce risk of medical paternalism.

The translation of the legal concept and test of mental capacity into clinical practice is complex and problematic and the execution of the law in clinical practice has been criticised recently by the House of Lords post legislative scrutiny committee.

In other jurisdictions where assisted suicide is legalised, there is no consistent definition or test of capacity for assisted suicide, although all jurisdictions have the requirement of ability to make the decision as a necessary part of the regulatory framework. Only in Oregon is there any guidance on capacity determination.

As with areas such as testamentary capacity, specific procedures and tests of capacity have been proposed but these have been criticised for being too prescriptive, burdensome and providing no more than legal indemnity for doctors.

These clinical, legal and ethical challenges provide the contextual foundations upon which this thesis is built.

3 Methodology and Methods

3.1 Introduction

This study aimed to explore the perspectives of senior doctors on the process and practice of mental capacity determination for terminally ill people requesting physician assisted suicide, were this practice to become legal in England and Wales. The primary objective was to inform, from a clinical perspective, the wider debate on the safeguarding elements in legalisation of physician assisted suicide for terminally ill adults in England and Wales.

The principal methodological approach used in this study was based on grounded theory, a qualitative methodology that has been widely used in healthcare research. The term 'grounded theory' defines both the methodological approach and the outcome of the research whereby researchers use a defined set of procedures with the aim of generating a 'grounded theory': a theory which is grounded in the data (Glaser and Strauss, 1967).

Grounded theory is a methodology that has evolved in various ways since it was first described in the late 1960s although some key features are common between interpretations.

In this chapter I will present in detail, the philosophical and methodological basis of the study, the methodological approach used, and the specific choices of methods used in conducting the study.

I will show how a grounded theory approach underpinned my approach to study design, recruitment, data collection and analysis, as I proceeded from the initial research question through to the emergence of a theoretical model.

I will also address the standards of rigour that I maintained in conducting the study, the ethical considerations in the design and execution of the study, and the *reflexive* stance that is essential to the emergence of a *credible* 'grounded theory' (Bryant, 2007b).

3.2 Methodological approach: Theoretical underpinnings

I chose a grounded theory approach because it facilitates the development of an iterative, inductive process whereby theory is developed and refined during data collection and analysis

and avoids imposing pre-existing hypothetical constructs. This methodology emphasises the participants' perspective and focuses on social interactions and experiences. It is often used in research areas where there is a dearth of data, with the aim of illuminating key issues and processes. This iterative way of working was appealing because the openness of the research question, and the spirit of exploration and discovery upon which the study was developed was well supported by the grounded theory approach. One of the key study aims was to explore the *process* of capacity assessment and this again pointed to a grounded theory approach as the methodologically best fit.

Grounded theory methodology claims to provide a rigorous set of processes with the aim of generating findings that are 'grounded in the data'. In its original conception (Glaser and Strauss, 1967), it was aimed ultimately to facilitate the generation of theory which can be used to explain and illuminate what is happening within the data. This theory can be 'substantive' e.g. explains what is happening within the situation being studied or, when raised conceptually further, can be 'middle range' or 'formal' e.g. applicable to other situations beyond the scope of the original study. Grounded theory therefore is at once an approach to qualitative enquiry, a method of analysis and a description of the theory potentially emerging from the study.

Grounded theory methodology uses a combination of inductive and deductive processes grounded firmly both in the data and the research literature by using a continuous interplay of data collection, data analysis and reflection on findings.

Grounded theory is not one unified methodology however, but a 'family of methods' (Bryant, 2007a) connected by a set of key concepts. According to Gelling (Gelling 2011), 'choosing to adopt a grounded theory approach is only the first stage in the process of selecting an appropriate research methodology'.

The following sections will explore the development of grounded theory methodologies from the original work by Glaser and Strauss and through its divergence and more recent interpretations by other methodologists, in order to establish the foundations upon which the specific methods used within this study have been built.

3.2.1 The development of Grounded Theory Methodology

GTM, a 'systematic, inductive, and comparative approach for conducting inquiry for the purpose of constructing theory' (Bryant, 2007a) originated from the work of sociological researchers Barney Glaser and Anselm Strauss, and was first explicitly described in their seminal 1967 work 'The Discovery of Grounded Theory' (Glaser and Strauss, 1967). Glaser came from a research background in quantitative methods whilst Strauss's background was in ethnographic field research using a 'symbolic interactionist' social paradigm. The core principles of symbolic interactionism as defined by Blumer (Snow, 2001) are:

- 1) People act towards things, including each other, on the basis of the meanings they have for them;
- 2) that these meanings are derived through social interaction with others, and
- 3) that these meanings are managed and transformed through an interpretive process that people use to make sense of and handle the objects that constitute their social worlds

Through explicit analysis and discussion about their own methodological approaches, particularly those used in their study 'Awareness of Dying' (Glaser and Strauss, 1965) Glaser and Strauss identified a set of fundamental approaches that characterised their developing methodology. They wrote their methodological text with the intention of galvanising sociological researchers to develop new ways of generating theory in an attempt to mark a departure from the predominant contemporary research that used 'statistical-quantitative, primary mass survey' methodology primarily used for 'theory verification'. (Bryant, 2007a). They did not intend that the work would offer 'clear cut procedures and definitions' but presented an approach which could be developed and built on by future researchers.

3.2.1.1 'Classical' Grounded Theory

In their original text, Glaser and Strauss (Glaser and Strauss, 1967) presented the *constant comparative method* comprising parallel processes of data collection and analysis seeking to 'systematically' abstract from the data in order to generate theory. They promoted flexibility in

the use of data whilst adhering to a rigorous approach to analysis, also presenting strategies for assessing studies to determine whether sufficient rigour had been employed to render them 'credible', 'plausible' and 'trustworthy'. In its original conception, Grounded Theory Methodology was intended to apply not just to studies using qualitative data, although it has subsequently been primarily used by qualitative researchers.

The constant comparative method comprises the systematic linking of data collection, data, coding and analysis, and is central to the Grounded Theory Methodology proposed by Glaser and Strauss. The method comprises four stages:

1. Comparing incidents applicable to each category (in a process of coding, comparing codes with data and writing of memos)
2. Integrating categories with their properties (raising the level of abstraction to show the relationships between categories with their properties and between categories with an ongoing process of memoing and theoretical sampling and moving toward theory generation)
3. Delimiting the theory (solidifying the theory, clarifying logic, removing non-relevant properties)
4. Writing the theory (using a combination of coded data, memos and theory to produce a written account).

This text also introduces other hallmarks of Grounded Theory Methodology including *theoretical sampling*, the progression from *open coding* to more *selective coding* and *theoretical coding*, using '*in vivo*' codes, *theoretical saturation*, *negative case analysis* and a lexicon emphasising *discovery and emergence of theory*.

3.2.1.2 'Straussian' Grounded Theory

In 1990, one of the original authors of 'The Discovery of Grounded Theory', Anselm Strauss and his collaborator Julia Corbin published 'The Basics of Qualitative Research' (with further editions in 1998 and 2008) in which they present a more procedural guide to conducting Grounded Theory research (Corbin, 2008, Strauss and Corbin, 1990, Strauss and Corbin, 1998).

In these texts, the authors begin by setting out the assumptions that underlie their methodology. These emphasise the relationship between emotion, action and interaction and the importance of shared perspectives. They explicitly take a 'pragmatic' approach to research by leading the researcher through the process of conducting a grounded theory study, but also try to make explicit some of the cognitive processes that the researcher goes through during the process of data analysis.

In addition to emphasising the core elements of *theoretical sampling* and *constant comparison*, new techniques are presented in this text for example *axial coding* (a process of systematically relating concepts to each other), using the *flip-flop technique* (looking at extreme ranges of a concept to explore its limits), and *red flag waving* (the process of conscientiously identifying the impact of personal biases on the data e.g. by questioning words such as 'never' and 'always').

The authors present examples of analysis and a scheme for interrogating emergent concepts in order to generate theory.

Advocates of Strauss and Corbin's vision of grounded theory methodology emphasise its attention to detail in defining specific procedures and techniques to generate theory from data which can be helpful for novice researchers e.g. (Cresswell, 2007) but this approach has also been criticised as too 'prescriptive' resulting in a risk of 'forcing the data' (Allen, 2010).

3.2.1.3 'Constructivist' Grounded Theory

In her influential 2006 text 'Constructing Grounded Theory' (Charmaz, 2006), Cathy Charmaz presents her interpretative perspective on grounded theory methodology. Whilst openly acknowledging the work of Glaser and Strauss as the foundations upon which her methodological approach is built, she consciously deviates from their original conception by asserting that data collection, analysis and theory development are *constructed* by the researcher and that separation of the researcher from the process and outcome is not possible and not necessarily desirable. She argues that the background, experience and theoretical lens

through which the researcher views their research problem should be explicit and the ways in which they might impact on the research should be explored within the research process.

In contrast to Glaser and Strauss' assertion that grounded theory methodology allows the researcher to see things 'as they are', Charmaz argues that a grounded theory study provides an interpretation of 'reality' which only exists in how it appears to the researcher. She contrasts her 'constructivist' stance with what she describes as the 'positivist' stance of Glaser and Strauss.

Charmaz nonetheless bases her approach in the core methods of Grounded Theory Methodology, including theoretical sampling, constant comparative analysis, using coding of progressive abstraction, memo writing and progress to theoretical saturation.

3.2.1.4 'Glaserian' Grounded Theory

Following his co-authorship of 'The Discovery of Grounded Theory', Barney Glaser has continued to publish books and articles furthering his original conception of grounded theory methodology and its methods and procedures (Glaser, 1978, Glaser, 1992, Glaser, 1998, Glaser, 2006, Glaser, 2008, Glaser, 2009, Glaser, 2011, Glaser, 2012, Glaser, 2014d, Glaser, 2014c, Glaser, 2014b, Glaser, 2014a).

As new approaches to grounded theory have been developed he has defended his original conceptualisation and counters the assertions of authors such as Charmaz that Grounded Theory is 'constructed'. He also maintains the position that grounded theory can be applied to quantitative analysis (Glaser, 2008) although there are few studies of this type, and there is a tendency to use grounded theory in mixed methods rather than purely quantitative research e.g. (Knigge and Cope, 2006).

Glaser asserts that the core of grounded theory methodology is,

...the careful tedium of the constant comparative method and theoretical sampling
(Glaser, 2002)

but is critical of the specificity of the analytical procedures proposed by Strauss and Corbin and what he views as Charmaz's preoccupation with accuracy over abstraction.

3.3 The grounded theory approach used in this study

Given that there are a range of methodological approaches and procedures claiming consistency with grounded theory methodology I chose to take an approach that would allow me flexibly and pragmatically to address the research question whilst adhering to the key defining procedures. As a result of this approach, this study cannot claim to follow precisely any 'school' of grounded theory methodology, but does adhere to the common elements presented across them.

The key elements that were planned at the outset in order to anchor this study within a *grounded theory approach* were:

1. The acknowledgment of *sensitising concepts* but the avoidance of preconceptions or hypotheses at the study outset.
2. Situating the study within a clear (though broad) philosophical framework
3. The use of a *theoretical sampling strategy*, based on how new data contribute to ongoing theory development.
4. The use of the *constant comparative method* whereby data collection and data analysis proceed concurrently and new data are compared to emergent themes and developing theory as the study progresses.
5. The use of an *explicit coding strategy* whereby initial 'open' coding is performed in order to identify emerging themes, proceeding to 'focused/selective coding' once a core category or central phenomenon emerges and theoretical coding thereafter.
6. An effort to *represent the participants' voices* through verbatim quotations and the use of 'in vivo' codes.
7. An analytic strategy which is inductive and continuously returns to the data to make sure that *developing categories and theories are fully supported by the data*.
8. The use of *memos* to record the development of ideas about evolving theory.

9. An attempt to develop and build upon theoretical sensitivity to the contextual factors and causal connections emerging from the analysis and *working toward the possibility of the discovery of a theory* or model to explain these connections and relationships.
10. Working toward *theoretical saturation* whereby data collection is discontinued once no further theoretical insights on a theoretical category emerge.
11. The completion of an *initial literature review* to anchor the study within what is known about physician assisted suicide and mental capacity determination, but no further literature review until after completion of the main analysis. Any initial insights gained from the literature review would be ‘bracketed’⁶ (Ahern, 1999, Tufford, 2012) and returned to following analysis of the study data.
12. The use of other sources of knowledge including the findings of other studies and the literature review to *place the findings of the main study in a situational context* and to further develop emerging theory.
13. Taking a *reflexive standpoint* and the explicit use of strategies such as keeping a journal to maintain reflexivity and rigour throughout the study.
14. Striving to *adhere to established standards of rigour* both for broadly defined qualitative research and for grounded theory research and making these standards explicit.

3.4 Demonstrating methodological rigour

In this section I will present the evaluation criteria I strove to meet whilst conducting this study. In Chapter 7, Section 7.3 I will discuss my reflections upon the extent to which these criteria were met.

There are a number of published criteria against which to measure the rigour of a qualitative study e.g. (Guba and Lincoln, 1988, Kuper et al., 2008, Malterud, 2001, Pope and Mays, 2006, Spencer et al., 2003, Whitemore, 2001, Silverman, 2004). The main texts on Grounded

⁶ Bracketing is the attempt to suspend, or hold in abeyance, preconceptions influenced by prior knowledge

Theory Methodology present standards for evaluating methodological rigour (Charmaz, 2006, Corbin, 2008, Glaser and Strauss, 1967, Strauss and Corbin, 1990, Strauss and Corbin, 1998) and criteria for evaluating Grounded Theory studies have also been proposed by other authors (Chiovitti and Piran, 2003, Cresswell, 2007).

Corbin and Strauss (Corbin, 2008) devote a chapter of the third edition of 'Basics of Qualitative Research' to presenting criteria for evaluation. In this chapter they highlight firstly the work of other qualitative researchers who have proposed criteria for evaluation (Charmaz, 2006, Chiovitti and Piran, 2003, Cresswell, 2007, Silverman, 2004) and particularly endorse the criteria of Charmaz.

Like Glaser and Strass, Corbin and Strauss propose *credibility* as a central indicator of quality in grounded theory research. As well as eight conditions under which a good quality study can be produced, they also propose ten criteria for judging the quality of research:

- 1) **Fit:** Do the findings resonate with the experience of both the professionals for whom the research was intended and the participants who took part in the study?
- 2) **Applicability or usefulness of findings:** Do they offer new explanations or insights?
Can they be used to develop policy, change practice or add to the knowledge base of the profession?
- 3) **Concepts:** Are the findings organised around concepts/themes?
- 4) **Contextualisation of concepts:** Does the researcher provide appropriate context e.g. historical or political?
- 5) **Logic:** is there a logical flow of ideas? Do the findings 'make sense'?
- 6) **Depth:** Do the descriptive details provide sufficient richness?
- 7) **Variation:** Has variation been built into the findings, meaning are there examples of cases that don't fit the pattern or that show differences along certain dimensions or properties?
- 8) **Creativity:** Are the findings presented in a creative and innovative manner? Does the research say something new or put old ideas together in new ways?

9) **Sensitivity:** Did the researcher demonstrate sensitivity to the participants and the data? Were the questions driving the data collection arrived at through analysis, or were concepts and questions generated before the data were collected?

10) **Evidence of memos:** Is there evidence of a growth in depth and degree of abstraction as the research moves along?

When considering the measures of rigour applicable to my study, I chose standards by which to judge the methodology and methods with the aim that they should withstand accepted standards of scrutiny in order for my findings to be judged *credible*.

For this reason I decided to take Strauss and Corbin's eight conditions that foster the construction of 'quality research' as the standard I aimed to meet as well as striving to produce a piece of work that would meet their ten criteria for judging the quality of the research.

In Table 2 below I present the eight 'conditions' proposed by Strauss and Corbin, and the ways in which I have set out to meet these in designing and carrying out this study.

Table 2: Criteria for evaluation of methodological rigour used in this study

Condition	Description of condition	How the condition was met
Methodological consistency	Generating credibility by using the key procedures of the chosen methodology	Demonstration of credibility by giving examples of the key procedures used in the study (see chapter 3)
Clarity of purpose	Stating clearly at the outset of the study whether it aims to provide description or to build theory	This study aimed to use a grounded theory approach to build theory which is grounded in the data.
Self-awareness	It is important that as an integral part of the research the researcher remains aware of their own biases and assumptions	A reflexive stance has been taken throughout this study and biases and assumptions have been explicitly stated (see particularly section 3.5.5)
Being trained in doing qualitative research	Generating a sound educational foundation in methods, data gathering and analysis.	This study was conducted as part of my PhD studies. Training and supervision in qualitative (specifically Grounded Theory) methodology and methods were integral to the process.
Having 'feeling' and sensitivity for the topic, for the participants and for the research	Being able to step into the shoes of the participants and accurately capture the viewpoint of participants	Theoretical sensitivity and reflexivity are explicitly addressed in chapter 3, sections 3.5.3 and 3.5.5
Willingness to work hard	A willingness to engage with the tasks associated with producing high quality qualitative research	A detailed description of the procedures used in the study is given in chapter 3
Willingness to relax and get in touch with the creative self	Being willing to brainstorm, turn things upside down, make theoretical comparisons and think about things in new ways	The emerging concepts and theory were frequently discussed in supervision, internal and external meetings and conferences with interdisciplinary colleagues.
Methodological awareness	Being aware of the implications of decisions made during the research process including anticipation of potential criticisms and attending to methodological problems as they arise.	Methodological decisions made in the process of the study have been explicitly described and reflections on whether the study meets the standards set at the outset are further discussed in chapter 7
Desire to do research for its own sake		A detailed rationale for the choice to undertake this study is integral to the presentation of this thesis.

3.5 Situating the self within the research design and process

As described in section 3.4, in grounded theory methodology, awareness of the self in the research process underpins a methodologically rigorous study. This section addresses how I situated myself in the research design, procedures and analysis.

3.5.1 Choosing the research design: Situating the research question

One of the early decisions to be made in designing the study was how methodologically to approach the research question. Working in a country where physician assisted suicide was currently illegal, I knew that I would not be able to access the doctor-patient encounter directly, but wanted to work with an England and Wales sample in order for the findings to be directly applicable to the domestic legal and clinical environment.

The scope of the project also needed to be feasible both in time and in scale. The data needed to be accessible and have the potential to add something novel to what is already known and a sufficient range and depth was needed within the data in order to generate meaningful findings.

The potential sources of data for this study were doctors and terminally ill adults who were intending to access physician assisted suicide. After carefully considering the possibility of attempting to access terminally ill adults for the study I decided that this would not fulfil the necessary pragmatic and theoretical criteria for the study. Firstly, accessing these patients would be very difficult. In the prevailing legal climate, terminally ill adults imminently intending to access physician assisted suicide might be reluctant to make themselves known, and even if they were prepared to do this, they would be small in number and with no reliable mechanism for identification. Secondly, the only feasible way to access these individuals would be through Swiss 'right to die' organisations and by definition these individuals would not be accessing physician assisted suicide under the domestic legal jurisdiction. I therefore decided to focus on gathering data from doctors.

In focusing my study on England and Wales I accepted the limitation that a study design addressing the process of mental capacity assessment would be, by definition, hypothetical. It had the potential advantage though that conducting a study before the possible legalisation of physician assisted suicide would allow me to gather data that might not be captured in a jurisdiction where physician assisted suicide was already legal. It would also present the possibility of gathering longitudinal data pre- and post-legalisation if assisted dying legislation were passed at some point in the future.

In considering potential approaches to the study design I sought to explore what approaches in this area had already been utilised. An early review of the pertinent research literature in 2007 showed a dearth of empirical studies examining mental capacity assessment for patients requesting physician assisted suicide among the very many empirical studies of other aspects of physician assisted suicide. The majority of published studies explored, using both survey and more in depth methods, attitudes toward physician assisted suicide and its legalisation from the perspective of various groups of patients, clinicians and the general public across a number of countries e.g. (Asai et al., 2001, Bachman et al., 1996, Bachman et al., 1997, Chapple et al., 2006, Chong and Fok, 2005, Cohen et al., 2006, Cohen et al., 1994, Di Mola et al., 1996, Douglas et al., 2001, Essinger, 2003, Fenn and Ganzini, 1999, Ferrand et al., 2006, Ganzini et al., 2006, Ganzini et al., 2003, Ganzini and Lee, 1997, Georges et al., 2006, Goy et al., 2006, Grassi et al., 1999, Hanlon et al., 2000, Lee et al., 1996, MacDonald, 1998a, MacDonald, 1998b, Materstvedt et al., 2003, Mularski et al., 2004, Portenoy et al., 1997, Ryyänen, 2002).

The only published empirical study of doctors attitudes to capacity assessment was a postal survey of forensic psychiatrists by researchers in Oregon (Ganzini et al., 2000a) which used a deductive, quantitative study design to examine the relationships between various a priori defined standards and processes for capacity determination. Whilst this study illuminated the ethical problem that the less acceptable doctors found the concept of physician assisted suicide the more stringent their standards of competence would be, it did not take into account the contextual factors that might influence this view or how it might vary under different circumstances. The quantitative methodology used allowed the authors to make statistical inferences from their data but not to go into further depth to explore the factors that might influence the quantitative findings and how these factors might play out within the clinical assessment.

3.5.2 Philosophical assumptions

In choosing a methodology, a number of philosophical assumptions are made by the researcher (Cresswell, 2007, Guba and Lincoln, 1988, Hallberg, 2006) and these should be made explicit in

order for accurate interpretations of the research to be made. The key philosophical assumptions informing my approach to this study are addressed in the following sections.

3.5.2.1 Ontological assumptions

Ontology concerns the nature of reality and its characteristics. Despite finding the constructivist epistemology of Charmaz appealing, I found the ‘post-positivist’ stance of Strauss and Corbin fit better with my research aims of trying to discover (albeit through an interpretive lens) how things ‘are’ within the situation of interest, particularly as I intended to use any insights gained to contribute to the wider debate on the legalisation of assisted suicide. Although taking a somewhat more ‘positivist’ perspective than that advocated by Charmaz, grounded theory methodology is based on the *constructionist* epistemology of symbolic interactionism which seeks to discover the world as it is experienced by those being studied.

The central ontological assumption I made in designing this study is that ‘reality’ is an individually interpreted phenomenon within the interpersonal intersubjective domain of the doctor patient relationship. Within this domain I have assumed that doctors participating in the process of mental capacity assessment will have different subjective experiences of these phenomena or ‘realities’. This project seeks to examine how doctors perceive these realities and how these perceptions might impact upon the assessment of capacity.

A post-positivist/relativist ontological position similar to that of Strauss and Corbin supports an interpretive approach to data collection and analysis.

3.5.2.2 Epistemological assumptions

Epistemology concerns the nature of knowledge and its acquisition. The basic epistemological assumption made in designing this study is that it is possible to generate meaningful knowledge through the systematic gathering and interpretation of data from interviews with doctors in order to elicit their perceptions of mental capacity assessment.

I wanted to explore the assessment of mental capacity as an interpersonal phenomenon, in which the interaction between doctor and patient leads to a decision being made, the outcome

of which has enormous gravity for the patient and potentially for the doctor, whichever conclusion is reached.

Another epistemological assumption I made was that I could not be objectively separate from the subject area, particularly given my interests, professional training and clinical experiences. A presumption of objectivity would be unlikely to reflect the interplay and interaction between myself as researcher, the respondents and the data; and also might curtail the *theoretical sensitivity*⁷ conferred by these experiences.

3.5.2.3 Axiological assumptions

Axiological assumptions are the values that the researcher brings to the study. The position of the researcher in the study can have important implications for the approach, the research design and the outcome of the study so it is essential that these assumptions are made explicit. In conducting this study I acknowledged that the subject matter, the data I chose to gather, my approach to analysis and my interpretation of the findings from the analysis were all shaped by my personal values and experiences.

In this study I took a reflexive stance whilst attempting to allow theory to emerge from the data. This stance attempts to recognise personal biases that might be influencing aspects of the process and outcome. Throughout this study I was mindful of how my own values might influence the study and strove to make these explicit.

3.5.2.4 Rhetorical assumptions

There are a number of rhetorical assumptions made when presenting a qualitative study and in developing my understanding of qualitative research it was necessary to learn the common language and structure that exists among the qualitative research community, and how this language and structure is employed in the construction of a qualitative report in order that its relevance, rigour and quality can be judged by others.

⁷ See section 3.5.3 for a definition further discussion of theoretical sensitivity within this study.

Qualitative studies are generally presented in a narrative style, with the voice of the researcher evident within the study, often explicitly, by using an active writing style. According to Cresswell there are common elements in the presentation of qualitative research comprising,

...the voices of participants, the reflexivity of the researcher, and a complex description and interpretation of the problem, and it extends the literature or signals a call to action.
(Cresswell, 2007)

In addition to these common elements there are several rhetorical structural conventions and procedures common to grounded theory studies. These include development of a clear 'analytic story', writing on a conceptual rather than a purely descriptive level, specifying how categories relate to each other and specifying the variations and conditions for relationships between categories (Strauss and Corbin, 1990).

Emergent theories and relationships between categories are often presented in diagrammatical as well as narrative form in order to provide a 'visual model' complete with conditions and directional arrows with a flow of causality from left to right. This model 'represents the culminating theory for the study' (Cresswell, 2007). In this thesis I have used a combination of both narrative and visual modelling to present emergent theory.

3.5.3 Theoretical sensitivity

According to Strauss and Corbin, theoretical sensitivity 'stands in contrast to objectivity' (Strauss and Corbin, 1998). It is the acknowledgement that each researcher comes to a study with their own ways of interacting with the data based upon their worldview, experience and philosophy. In this way, findings are the 'product of data *plus* what the researcher brings to the analysis' (Corbin, 2008). Theoretical sensitivity is 'an awareness of the subtleties of meaning of the data' (Strauss and Corbin, 1990).

Glaser emphasises theoretical sensitivity in his grounded theory methodology but acknowledges that explicit discussion of this was absent in the original text (Glaser, 1978)

According to Strauss and Corbin (Strauss and Corbin, 1990) sensitivity can occur in two ways:

- 1) The researcher can enter the process with personal and professional experiences and knowledge which allow them to be sensitive to the emergent concepts and theory
- 2) Sensitivity can be developed during the analytic process as 'insight and understanding about a phenomenon increase as you interact with your data'.

In Section 1.1, I described some of the professional and personal experiences that initially led me to develop this study. During the course of the study I adhered to the process of concurrent data collection and analysis which allowed me to develop 'sensitivity to concepts, their meanings and relationships' (Strauss and Corbin, 1990).

Strauss and Corbin advise that there needs to be a balance between 'science and art' whereby the creativity conferred by theoretical sensitivity is moderated by conscious adherence to method. They propose strategies to maintain this balance which I kept in mind throughout the study.

These strategies are:

1. Periodically step back and ask: What is going on here? Does what I think I see fit the reality of data?

During the study process I had two periods of maternity leave (in 2010 and 2012), one of which provided a gap in my data collection. These periods were positive in the process of analysis because they enforced 'stepping back' and made me rethink and re-examine my analyses upon each return to the study having considered them at a distance.

2. Maintain an attitude of scepticism: explanations should be regarded as provisional and always need to be checked out.

Throughout the study I adhered to the constant comparative method and at various key stages I discussed my emerging ideas with my supervisors and research group, giving examples of data that supported them (as well as data that seemed not to support them). This process was very helpful in shaping my ideas and in particular dismissing provisional ideas that did not fit with the data.

3. Follow the research procedures

Despite their ideological and methodological differences all of the main texts on grounded theory methodology advocate following the key research procedures as a way of ensuring rigour in the study. Strauss and Corbin recommend adherence to the research procedures in order to 'break through biases' and 'examine at least some of [your] assumptions that might otherwise affect an unrealistic reading of the data'. They particularly advocate concurrent sampling and analysis and systematic coding as ways to minimise bias in the study: procedures that have been adhered to in the conduct of this study and will be described in further detail as the chapter progresses.

3.5.4 Sensitising concepts

The notion of sensitising concepts in qualitative research was first described by Blumer, ((Blumer 1969 in (Bowen, 2006)) as ideas to pursue and sensitise the researcher to ask particular questions about the topic of interest. Charmaz described sensitising concepts along with guiding interests and disciplinary perspectives as 'points of departure for developing, rather than limiting our ideas' (Bryant, 2007a). She also described these as 'vantage points' but cautioned that there was a need to remain open to other information seen and sensed during early stages of data collection. She contrasted sensitising concepts with the testable hypotheses of quantitative research as the starting point for an inductive rather than deductive process. Sensitising concepts can also guide further data collection once early data have been collected. The use of sensitising concepts has been critiqued however because of the potential for distracting the researcher from more important areas of enquiry (Bowen, 2006) although Charmaz counters this view by advising that sensitising concepts are dispensable if they 'prove to be irrelevant'.

In developing the research study I was interested in the 'real world' assessment of capacity for adults requesting physician assisted suicide and the intersubjective aspects of the assessment process. As a clinician who is frequently involved in the assessment of capacity I was aware that

decisions about whether a patient has mental capacity to make a particular decision are often not straightforward and that there might be conflicting views about the same patient.

My initial 'point of departure' therefore was to examine the relational processes involved in capacity determination, both between doctor and patient but also between the doctor and others involved in the decision making process.

Further sensitising concepts emerged during a trip to Oregon in 2009 during which I met with several individuals involved professionally with physician assisted suicide who allowed me to audio record interviews with them. These interviews were conducted before main data collection commenced and provided valuable information about how physician assisted suicide is practiced in a jurisdiction where it is legalised. Within our dialogue I was able to explore some of the ideological, ethical and clinical challenges of physician assisted suicide and develop some initial ideas and 'hunches'.

During these conversations I was particularly struck by one interviewee's description of knowing in the relationship between assessor and patient. She introduced ideas about knowing the patient, particularly limitations and barriers to knowing which seemed to be important. A tentative idea emerged that in order to manage the relationship between assessor and patient there needed to be some imposed limitations to knowing and that knowing the patient 'too well' was not necessarily felt to be desirable for either patient or clinician.

Another seemingly unrelated sensitising concept arose from my reading of the general literature on the conceptualisation of capacity determination as a process that could not be value free, and in particular the findings of the study (Ganzini et al., 2000a) showing that the value base of the doctor impacted on their views on mental capacity for assisted suicide. I saw the relationship between values and approach to assessment as another potential line of enquiry.

These two sensitising concepts were at the outset of data collection rather unformed and I did not have a clear sense of how they might interrelate or how relevant they would be to my study as it developed.

These concepts however became increasingly important as data collection and analysis progressed. As I will describe in the section on development of the topic guide (section 3.6.4.4), a progression was seen from an initial focus on pathways of assessment and referral toward a greater focus on the intersubjective relationship between doctor and patient, including the values that informed the approach to relationship building. My first working topic guide, for example, contained only one question concerned with ‘knowing the patient’ but by the last iteration had expanded into a substantial section of the topic guide based on its relevance to the doctors interviewed and its central place in the developing conceptual framework.

As I will explore further in chapter 5, once the main data analysis was completed I returned to the interviews I conducted in Oregon to reconsider the conversations that had taken place during that visit. Through this process I was able to contextualise my findings and gather new insights into how ‘knowing’, values and approach to decision making compared between the two sources of data, which added a further dimension to the theoretical model that had emerged from analysis of the main interviews with doctors in England and Wales.

3.5.5 Reflexivity

Reflexivity is ‘the researcher’s scrutiny of his or her research experience, decisions, and interpretations in ways that bring the researcher into the process and allow the readers to assess how and to what extent his or her interests, positions, and assumptions influenced the research’ (Bryant, 2007b).

There were two key areas in conducting this study where maintaining a reflexive stance was vitally important. Firstly, in examining and reviewing my own values and beliefs around the practice and legalisation of assisted suicide for the terminally ill; and secondly in reflecting on my relationship with the doctors I interviewed and how this may have influenced the content of the interviews and how I interpreted what was said in them. The following two sections expand upon these reflections.

3.5.5.1 Personal values and beliefs

The debate on legalisation of physician assisted suicide for the terminally ill is polarising and many have strongly held views either in support or in opposition to legalisation. As shown in the survey of senior doctors' views described in more detail in section 5.2.1, these are associated with factors such as religious belief and exposure to care of dying people. In presenting my main study findings I will show that doctors' ideas about legalisation of physician assisted suicide were influenced by a number of contextual factors such as beliefs about the meaning of suffering and the intrinsic value of the process of dying.

My own views on the legalisation of physician assisted suicide developed during the process of conducting this study. At the outset of the study I had worked in palliative care for a short time but most of my clinical experience was in acute medicine, surgery and psychiatry. As a non-religious person from a non-religious family I did not have a view about the value of life in a religious context, and my broadly liberal political views have a basis in valuing personal autonomy and choice. Given this background I might be expected to hold a view in support of physician assisted suicide, but my personal views were less clear. My experience in psychiatry had taught me about the relationship between suicide and mental disorder and my training had emphasised suicide risk assessment and prevention. My reading on ethical issues at the end of life, particularly the Ms B case (Keown, 2002) had shown me that clinical decisions at the end of life are complex and often divisive. I had been fortunate to meet one of the psychiatrists involved in the process of capacity determination in the Ms B case and was struck by how affected he was by the decision he had made some years on. As a trainee psychiatrist I was aware that if assisted suicide were legalised, difficult capacity decisions might fall to me or doctors like me.

During the process of conducting the research I became increasingly familiar with the complexities and nuances of the ethical arguments on both sides of the debate. Working as a psychiatrist in a hospice for over a year during the course of my PhD studies I gained a valuable insight into the patient experience of nearing the end of life and the impact of psychological

suffering on the quality of life of dying patients. I was asked to assess a number of patients who had expressed a desire for hastened death in the context of their terminal illness and was asked directly by one patient to help him end his life. I also conducted an epidemiological study which included the examination of the relationship between depression and desire for death in patients with terminal illness, and in the course of that study personally interviewed over 100 patients who were nearing the end of life (Goodwin et al., 2012, Hayes et al., 2012, Price et al., 2011, Rayner et al., 2011). These experiences, in line with the results of the survey showing that caring for the dying is associated with views less in favour of the legalisation, resulted in development of increasing sense of caution about the legalisation of physician assisted suicide for the terminally ill.

Because of a growing awareness of this perspective, I was careful to try to maintain a stance in the interviews which was curious and open. Within the main sample were doctors holding a wide range of views on physician assisted suicide and with a range of backgrounds, specialities, beliefs and experiences. Within the interviews the doctors' views on physician assisted suicide were discussed but I was careful not to discuss my own perspectives and when asked directly for my opinion tended to reflect on the range of opinion given by other participants. It was interesting to note however the feedback of several participants, that in giving time to detailed consideration of assessing mental capacity for physician assisted suicide, some felt less sure about their original support for legalisation. This view reflected my own journey and development of ideas as the study progressed.

3.5.5.2 Relationship with research participants

In a memo I made during a phase in which I was preparing for a set of interviews and reviewing the transcripts of earlier interviews I noted:

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On reading the first transcripts of interviews with UK doctors I became aware that in my questions I often assumed a shared identity and or point of view. I sometimes referred to 'we' as doctors and sometimes 'you'. On closer reading of these and recalling the conditions of the interviews I came to realise that if I felt comfortable with and identified personally and/or professionally with the interviewee I would tend to use more inclusive 'we' language whilst with doctors I did not identify with so

closely I tended to use language which separated me more, using 'you' or 'doctors' as though I was not also one.

This observation illustrates some of the challenges I faced in the process of data collection. As a doctor I shared a common training pathway with my interviewees; as a psychiatrist I shared a specialty with some of my interviewees but not others; as a researcher I felt 'other' than my interviewees; as a psychiatrist working in a hospice environment I felt that I had more in 'common' with the palliative care professionals than many of the other doctors and noticed that my use of language was more 'inclusive' when talking with them,

NE_Doc 2 (Pall care)

I wonder if you would be happy for us to think in a little bit more detail about how we might assess mental capacity for this group?

than for example with the surgeons in the sample,

NE_Doc 3 (surgeon)

Can you perhaps give me your initial thoughts about what you might start to think about in terms of the process around that, about deciding whether they had capacity to go through with it?

The use of 'inclusive' or 'exclusive' language in the interviews was not limited to feeling more comfortable talking with some doctors than others by virtue of specialty: the rapport developed in the interview appeared to influence my style of questioning. In one interview in particular, I felt I struggled to develop rapport from the outset because I felt very 'junior' to the doctor I was interviewing. Aware of wanting to appear 'neutral' at the outset of the interview, I introduced myself as a PhD student. The following is an excerpt of the subsequent exchange:

RES I had understood you were a psychiatrist.

INT That's right. So I'm a psychiatrist, but I'm studying for a PhD.

RES Okay....Mm-mm. Can you tell me, who's supervising you again?

This somewhat adversarial beginning influenced me to use a rather formal style and unless referring to matters directly related to our verbal interaction, questions related to 'you' rather than 'we' or 'us' e.g.

Okay. And in terms of the process that you would want to go through in order to determine whether that patient has the capacity, would you mind taking me through the sort of steps that you'd like to follow and how you might approach that assessment?

In his book 'Elite and Specialised Interviewing', Dexter (Dexter, 2006) addresses some of the issues that might be encountered when interviewing experts, or 'people in important or exposed positions'. He acknowledges the challenges in interviewing elite participants including interviewees wanting to clarify the interviewer's provenance before being comfortable to continue: 'a good many interviewees will want to know the sponsorship' and will ask questions of the interviewer to 'find out whether the interviewer is the sort of person the interviewee wants to talk freely to'.

The experience described above contrasts with other interviews in which the interviewee and I were able to develop an easy rapport irrespective of professional similarities or relative seniority. An example here is of an interaction with female GP of a similar age to myself. I noticed when analysing the interview how the language I use at times implies a shared view of the problem,

INT	So from your point of view, am I right in thinking that you feel that it's rather unsatisfactory perhaps, the way that we're...
RES	It is.
INT	... we as doctors are asked to assess capacity?

Once I noticed these patterns in earlier interviews I was much more aware of myself in relation to the interviewees particularly my 'insider/outsider' status (Corbin-Dwer, 2009) and the impact of how I defined myself (Richards and Emslie, 2000).

3.6 Research procedures

In the following sections I will present in detail the research procedures that were used in this study and the basis for their selection. The procedures are presented concurrently but in accordance with the grounded theory approach, the procedures of sampling, data collection, coding and memoing were not a linear process. Using the core principles of theoretical sampling and constant comparative analysis, these procedures were interwoven throughout the study process.

3.6.1 Ethical considerations

Research ethics approval for the study was originally granted in 2006 (NRES number 06/Q0706/36) and an amendment to this approval was granted in 2009 in order to extend the sample to non-psychiatrists.

The main ethical considerations in this study were,

1. Providing adequate information to ensure that informed consent had been gained prior to participation
2. Ensuring that participants were aware they are able to withdraw from the study at any time.
3. Ensuring that confidentiality of participants was maintained throughout the study
4. Safe storage of data (both audiorecorded and transcribed)

In the following sections, the ways in which these considerations were met will also be demonstrated.

3.6.2 The timing of the literature review

Within the methodological literature on grounded theory, discussion of the necessity for and appropriate timing of the literature review has been controversial and polarising. In their original work Glaser and Strauss emphasised the emergence of theoretical codes and the inductive process of theory generation (Glaser and Strauss, 1967). Glaser in particular has warned against being 'led' by the literature and not allowing theory to fully emerge from the data as a result (Glaser, 1978). Other arguments against early literature review include avoiding recognised or unrecognised assumptions about the data and avoiding a focus on the literature rather than the data. Strauss has since adopted a more pragmatic permissive stance on literature review (Strauss and Corbin, 1998) arguing that it can enhance theoretical sensitivity, direct theoretical sampling and avoid conceptual pitfalls. Other arguments for early literature review are that it is often necessary in order to meet the requirements of ethics or other research committees. In their discussion of the literature review and reflexivity in grounded theory research, McGhee and Marland (McGhee et al., 2007) compare their alternate strategies to the literature review

and justify these in relation to their own experience within their fields of study, their initial approaches to their studies and the pragmatic requirements of their PhD programmes. One solution they propose to this dilemma is to conduct an initial literature review in order to identify the researcher's perspective as the study begins and provide justification for launching the grounded theory study and then conduct a further review of the literature that links existing research and theory with emerging concepts.

Having chosen an area of study which was aligned with my professional practice and interest and that of my supervisor and research department, I began the study familiar with the general literature on mental capacity determination and some of the vast literature on assisted suicide; however one of the key factors that pulled me toward a study exploring mental capacity assessment for physician assisted suicide was a lack of literature here in relation to other aspects of the assisted suicide debate and experience. Much of the available literature was theoretical, and at the time of data collection only one empirical study had addressed this issue directly (Ganzini et al., 2000a).

Prior to data collection I was not at all familiar with the body of theoretical and empirical literature related to the core concept of 'knowing the patient' that subsequently emerged in my study. An exploration of this literature and its relationship to the findings of my study therefore forms the basis of Chapter 6 and consideration of this literature helped me to situate my findings within what is already known about the relationship between knowing and decision making in healthcare contexts and examine how my findings advance this extant knowledge.

3.6.3 Sampling

Qualitative sampling differs from that used in quantitative methodology in that it does not seek to generate results which can be statistically generalised to the whole population of interest. Instead, the aim is to reflect the range of opinion within the sample of interest, and explore this range at greater depth. In qualitative methodology a strategy of *purposive sampling* is used to select a sample which is likely to reflect this range of opinion. This form of non-proportional

sampling involves selecting the sample subjectively, based on the likelihood that the sample represents the population of interest.

Grounded theory methodology additionally specifies the technique of *theoretical sampling*.

Because data collection and analysis occur concurrently in grounded theory methodology, data are gathered in order to build on and refine emergent categories from analysis of earlier data.

Categories can therefore be *theoretically saturated*. According to grounded theory methodology, initial sampling provides only a point of departure, and because categories are not known in advance, the full sampling strategy cannot be predetermined.

In their original work, Glaser and Strauss define theoretical sampling as

...the process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges. (Glaser and Strauss, 1967)

Glaser, Strauss and Corbin, and Charmaz all endorse theoretical sampling as a central procedure in grounded theory methodology.

The strategy of theoretical sampling is variously interpreted in the Grounded Theory literature, and some studies purporting to use theoretical sampling have been criticised for their misinterpretation of this sampling theory. Charmaz has identified four common mistakes made by researchers setting out to theoretically sample:

- i) Sampling to address initial research questions
- ii) Sampling to reflect population distributions
- iii) Sampling to find negative cases
- iv) Sampling until no new data emerge

In their paper 'Demystifying Theoretical Sampling in Grounded Theory', Breckenridge and Jones (Breckenridge J and Jones D, 2009) seek to clarify the processes and procedures of theoretical sampling by exploring the key theorists' accounts and how these have been interpreted by subsequent researchers using Grounded Theory Methodology. They compare Glaser and Strauss's original conceptualisation of a theory driven but creatively open process with Strauss and Corbins's more prescriptive three stage procedure (open sampling, relational sampling and

variational sampling) which corresponds closely to their three stages of coding. They compare the inductive nature of studies that utilise theoretical sampling from the outset with qualitative studies that begin with a deductive approach to generating an initial sample, but pick up on Walker and Myrick's assertion (Walker and Myrick, 2006) that 'initial ideas can benefit theoretical development by providing a point of departure and by raising important preliminary questions'. One of the key difficulties in using a theoretical sampling strategy is where and with whom to begin, and here Breckenridge and Jones offer the pragmatic solution that,

...theoretical sampling may involve the purposeful selection of an initial starting point before moving into theoretical sampling when data analysis begins to yield theoretical concepts (Breckenridge J and Jones D, 2009)

3.6.3.1 Sampling strategy

The initial strategy I used was one of purposive sampling. I wanted to explore the perspectives of doctors who had not necessarily thought deeply about this matter in the past or publically engaged in the assisted dying debate because these would be the doctors grappling with, maybe for the first time in our interview, their own views and attitudes in this area. My strategy therefore was to try to identify doctors working in local practice who had no prior public profile related to the assisted suicide debate.

I therefore chose to sample two groups of medical professionals:

1. Doctors who are likely to make the initial assessment of a terminally ill adult who has requested physician assisted suicide: A sample potentially including general practitioners, palliative care physicians, oncologists, and geriatricians.
2. Psychiatrists, including liaison psychiatrists, old age psychiatrists and general psychiatrists: The clinicians who would likely be asked to make assessments of mental capacity in patients who have requested physician assisted suicide.

3.6.3.2 Recruitment strategy

In my previous survey of doctors' attitudes to physician assisted suicide, ethical approval was granted to undertake a qualitative study of psychiatrists' perspectives of mental capacity assessment for terminally ill patients requesting physician assisted suicide (REC reference

06/Q0706/36). The psychiatrists in that original survey sample were asked to provide their contact details if they were willing to be approached to participate in the qualitative study and ten psychiatrists from several geographical locations provided their contact details.

With this recruitment strategy psychiatrists would initially be contacted by letter to ascertain whether they would still be willing to participate. If they responded positively, further potential participants (including other psychiatrists) would be identified from within their Primary Care Trust (PCT) and geographical area. This information is freely available and within the public domain. Potential participants would then be contacted by letter with an invitation to participate in the study. The aim was to recruit three different groups of participants one from the south of England, one from the North of England and one from Wales, to capture potential variation by location of practice.

3.6.3.3 Generating the initial sample

Of the original ten psychiatrists who were initially contacted regarding participation in the study, two agreed to be interviewed-one from the north of England and one from the South of England. Without a psychiatrist from Wales identified, a decision was made to make contact with a liaison psychiatrist based in Wales who had not participated in the original study and they agreed to participate. Therefore as planned there were three geographically distinct centres: one in urban North London, one in the rural north west of England and one in suburban Wales.



Figure 1: Representation of recruitment strategy for each geographical area

Once these three participants had been identified, searches of publically available information on local medical professionals (e.g. Local Commissioning Group, general practice and hospital websites) were completed and potential study subjects identified. These doctors were contacted by letter and invited to participate⁸.

In the north of England recruitment area 90 potential interviewees were identified and contacted, 22 of whom responded. Five of the 22 agreed to participate, one was unsure but later declined to participate and 16 declined to participate. Of the five who originally agreed to participate, three were interviewed. The other two did not respond to attempts to schedule an interview. Three interviews took place, all by telephone. The north of England sample therefore comprised one psychiatrist (who had agreed to participate following the original survey), two surgeons and one consultant in palliative care.

⁸ A copy of the letter of invitation sent is shown in Appendix 1: Invitation letter to potential study participants

In the south of England recruitment area, 135 potential interviewees were identified and contacted of whom 31 responded. Eight of the 31 agreed to participate and 23 declined. Eight interviews took place, seven face to face and one by telephone. The south of England sample therefore comprised three psychiatrists (one of whom had agreed to participate following the original survey), five general practitioners and one general surgeon.

In the Wales recruitment area 94 potential interviewees were identified and contacted of whom 26 responded. Fourteen of the 26 declined to participate in the study, ten agreed to participate and two indicated that they might be willing to participate but requested further information before agreeing to participate. The two who were undecided at first later decided not to participate. Of the ten who agreed to participate, nine were interviewed; the tenth did not respond to attempts to schedule an interview. One interviewee suggested at interview that I contact their colleague for interview and they agreed to participate after being contacted, therefore ten interviews took place, six face to face and four by telephone. The Wales sample therefore comprised six psychiatrists (one of whom had agreed to participate following being contacted prior to the main recruitment phase), two general practitioners, a consultant in palliative care and two oncologists.

3.6.3.3.1 Describing the sample

Table 3 shows the characteristics of the individuals in the interview sample. The sample comprised 24 participants, 12 male and 12 female. Four were from the north of England, nine from the south of England and 11 from Wales. Twenty practiced in an urban/suburban area and four in a rural area. The sample comprised nine psychiatrists, eight general practitioners, and seven doctors working in secondary care: two in oncology, three in surgery and two in palliative care. Years in speciality ranged from 4-27.

Fifteen of the interviews were conducted face to face and nine were conducted by telephone.

Table 3: Characteristics of the interview sample

	Identifier	Interview type	Region	Specialty	Subspecialty	Years in specialty	Gender	Ethnicity	Religion
1	Wales_Psych1	Face to face	Wales	Psychiatry	Old age psychiatry	4	Male	Pakistani	Muslim
2	SE_Psych1	Face to face	South East England	Psychiatry	Liaison Psychiatry		Female	White British	Not stated
3	NE_Psych1	Telephone	North East England	Psychiatry	Old age psychiatry		Female	White British	Not stated
4	NE_Doc1	Telephone	North East England	Surgery	Colorectal surgery	12	Male	White British	Christian (other)
5	NE_Doc2	Telephone	North East England	Palliative Medicine	N/A	18	Female	White English	Not stated
6	NE_Doc3	Telephone	North East England	Surgery	General surgeon	7	Male	White British	Christian (Church of England)
7	SE_GP1	Telephone	South East England	General Practice	N/A		Female		Not stated
8	SE_Doc1	Face to face	South East England	Surgery	General surgeon		Male	White British	Atheist
9	SE_GP2	Face to face	South East England	General Practice	N/A	11	Male	White British	Atheist
10	SE_GP3	Face to face	South East England	General Practice	N/A	14	Male	White British	No religion
11	SE_GP4	Face to face	South East England	General Practice	N/A	6	Female	Mixed other	No religion
12	SE_GP5	Face to face	South East England	General Practice	N/A	8	Female	White British	Christian (Roman Catholic)
13	SE_GP6	Face to face	South East	General Practice	N/A	18	Male	White Irish	No religion

Identifier		Interview type	Region	Specialty	Subspecialty	Years in specialty	Gender	Ethnicity	Religion
			England						
14	SE_Psych2	Face to face	South East England	Psychiatry	General adult psychiatry	16	Male	White British	No religion
15	Wales_Doc1	Telephone	Wales	Oncology	N/A	17	Male	White British	Not stated
16	Wales_Doc2	Telephone	Wales	Oncology	N/A		Male	White British	Not stated
17	Wales_Doc3	Face to face	Wales	Palliative Medicine	N/A	6	Female	White Welsh	Christian (Church of England)
18	Wales_GP1	Face to face	Wales	General Practice	N/A	21	Female	White Welsh	No religion
19	Wales_Psych2	Face to face	Wales	Psychiatry	General adult psychiatry	6	Female	Other white British	Christian (Roman Catholic)
20	Wales_GP2	Face to face	Wales	General Practice	N/A	27	Female	White Irish	Not stated
21	Wales_Psych3	Face to face	Wales	Psychiatry	General adult psychiatry		Female		Not stated
22	Wales_Psych4	Face to face	Wales	Psychiatry	General adult psychiatry	11	Male	White British	No religion
23	Wales_Psych5	Telephone	Wales	Psychiatry	General adult psychiatry	7	Female	White British	Christian (other)
24	Wales_Psych6	Telephone	Wales	Psychiatry	Liaison psychiatry	14	Male	White British	No religion

Within the sample the majority of the psychiatrists were based in Wales and the majority of the general practitioners were based in south east England. Table 4 shows the professional groups by region.

Table 4: Professionals by region

	South of England	North of England	Wales	Total
Psychiatrist	2	1	6	9
General practitioner	6	0	2	8
Other doctor	1	3	3	7
Total	9	4	11	24

3.6.3.3.2 Process of informed consent to participate

Prior to interview each participant was sent an information sheet detailing the nature and purpose of the project and the relevant ethical considerations⁹ and a consent form to complete before the interview confirming that they had read and understood the information given, understood that they could withdraw at any time, and whether they agreed to take part in the study¹⁰. Prior to beginning each interview I gave the participants an opportunity to ask questions and clarify any areas they were unsure about. I again summarised the purpose of the study at the beginning of each interview and checked again that the participant was willing to participate before continuing.

3.6.3.4 Theoretical sampling

Theoretical sampling is the process whereby the researcher aims to ‘develop the properties of his or her developing categories or theory’ and ‘seeks people, events or information to illuminate and define the boundaries and relevance of the categories’ (Charmaz, 2006).

In this study I used three theoretical sampling strategies: Firstly, once the core category of ‘knowing the patient’ had been identified I proceeded to seek further information about this category, its boundaries and relationships within subsequent interviews that had already been planned. This strategy is reflected in the development of the topic guide to emphasise

⁹ See Appendix 2: Information sheet for participants

¹⁰ See Appendix 3: Consent form for participants

exploration of this category as described in section 3.6.4.4 and in the greater focus on 'knowing' within later interviews.

Secondly, once a model of the relationship between knowing the patient and the process of capacity assessment had emerged from my original sample I proceeded to sample outside of my original sampling frame to explore whether this model held within a different situation. This is a process also referred to as 'discriminant sampling' (Cresswell, 2007). As described in section 4.5 I interviewed two members of an organ transplant team about their perspectives on the relationship between knowing the patient and decision making.

Thirdly, I recontacted my main sample and asked the members to feed back their views on my emergent findings. I particularly sought to elicit areas where my emergent theory did not 'fit' with individual perspectives. The information gained from this process was valuable as a process of respondent validation, as all of those who provided feedback said that the findings I presented to them fit with their own perspective on the situation. This feedback is presented in more detail in section 3.11.

3.6.3.5 Setting

The chosen settings for the interviews were based on two main factors:

1. Convenience/preference of the participant
2. Pragmatic concerns

As described in section 3.6.3.3.1 the majority of the interviews were conducted face to face, but some were conducted by telephone. My preference if possible was to conduct face to face interviews but in some cases the participants preferred a telephone interview or did not have time to set aside for a face to face interview.

For the face to face interviews, all but two took place in the doctor's place of work-usually in their office or surgery. The two exceptions to this were chosen in preference by the participants-one took place in the participant's home and the other took place at the headquarters of the Royal College of Psychiatrists.

The exception to being led by the preference of the participants for the interview setting was for the north of England participants. The doctors were located in a rural and fairly remote area and at the time the interviews were being scheduled a major incident had rendered the area virtually inaccessible, so the participants and I agreed that a telephone interview would be the most pragmatic option at that time.

3.6.4 Data collection

In grounded theory methodology, data can be collected in a variety of ways although in practice many grounded theory studies are based on a set of in depth unstructured or loosely structured one to one interviews. In this study I chose to use in-depth one to one interviews for the purpose of gathering rich data by exploring each participant's perspectives in detail. Because grounded theory studies are inductive and exploratory, there is no imposed framework to the interviews, especially in the early stages, but loose topic guides are often used at the outset of the study and developed inductively as the study progresses (Sbaraini et al., 2011). As data collection proceeds, the topic guides are refined in order to explore emerging categories and theory and de-emphasise areas which are no longer yielding new data or prove to be irrelevant to the core category.

3.6.4.1 Developing the initial topic guide

Whilst being mindful of keeping a very open approach to the interviews, the initial topic guide was based on my reading of the limited literature related to mental capacity assessment for physician assisted suicide, the experiences and insights gained from my visit to Oregon and discussion with my supervisors and other colleagues regarding possible areas interest. The initial topic guide also provided me with a prompt for information to be given to the participant at the beginning of the interview and also some basic questions about the participant's professional role and experiences.

3.6.4.2 Pilot interviews: testing the topic guide and scope of the interviews

Prior to finalising the first iteration of the topic guide and recruiting for the study I invited two doctors known to me professionally (a psychiatrist and a palliative care physician) to participate separately in a pilot interview. The purpose of the pilot interviews was twofold,

- 1) Given the sensitive and emotive nature of the study, to ascertain whether the topic of enquiry and the way the interview was conducted was acceptable and to make modifications to this if necessary.
- 2) To gather feedback about the project and topic guide and modify these according to the feedback gained.

The interviews were conducted according to the same ethical procedures used in the main study-the participants were asked to consent to being interviewed and for their interviews to be audiotaped and analysed, although these interviews did not form part of the main body of the study.

The feedback from the first pilot interview (with the palliative care physician) was that whilst the line of enquiry was acceptable and the subject of relevance and interest, it felt uncomfortable and exposing to be asked about views on the acceptability of legalisation of physician assisted suicide so early in the interview. The interviewee suggested that this would be easier to broach if it were brought up later in the interview if the subject hadn't arisen naturally as the interview progressed.

I took this feedback forward into the second pilot interview (with the psychiatrist) who agreed that any discussion about views on legalisation should be volunteered by the participant during the interview or be left until the end.

The information provided prior to the interview, the consent process and the way the interview was conducted was acceptable to both interviewees and no changes to these were suggested.

The first topic guide that was used in the main study after refinement had been made according to the feedback above is shown in Appendix 4: Initial topic guide.

3.6.4.3 Development of the interview strategy

I approached the main interviews with a very broad and flexible strategy, but in order to shape my enquiry I bore in mind three main areas for exploration:

1. Who is the participant, what is their area of practice and within this area of practice what is their exposure to and experience with terminally ill patients and assessment of mental capacity?
2. Within the participant's own experience and area of practice what are their perceptions on the purpose, principles and process of mental capacity assessment?
What are the problematic areas and issues in their experience?
3. What are the participants' perceptions of mental capacity assessment in the context of patients requesting physician assisted suicide and how do these relate to their personal and professional experience and wider context?

Over the course of the data collection process these areas provided a basic structure of which I maintained an awareness, but many of the interviews departed from this structure as new insights and perspectives emerged, and I encouraged this in the interviews.

There were some key stages during the main data collection process where changes were made to the initial approach in order to improve the quality of data collection but also to make the interviewees feel more comfortable.

Following completion of the first two interviews in the main data collection (August 2009), I reflected that I had spent quite a proportion of the interview explaining and clarifying areas of the most recent Assisted Dying Bill. This had impacted on the flow of the interviews and meant that the interviewees felt it necessary to ask me for information. This had an impact upon the power dynamic within the interview and put me in the reluctant position of being the 'expert'. I solved this by producing a short written summary of the Assisted Dying Bill which was sent to

the participants before the interview¹¹. I was mindful that participants were busy and would be unlikely to have time to read the information until just before the interview so I ensured it was very brief and focused. It served two purposes; firstly to orientate the interviewee to the subject area, and secondly to provide a source of information that participant could be directed to during the interview should the need arise. This strategy worked very well both in preparing the participants and redressing the imbalance of 'expertise'.

3.6.4.4 Development of the topic guide

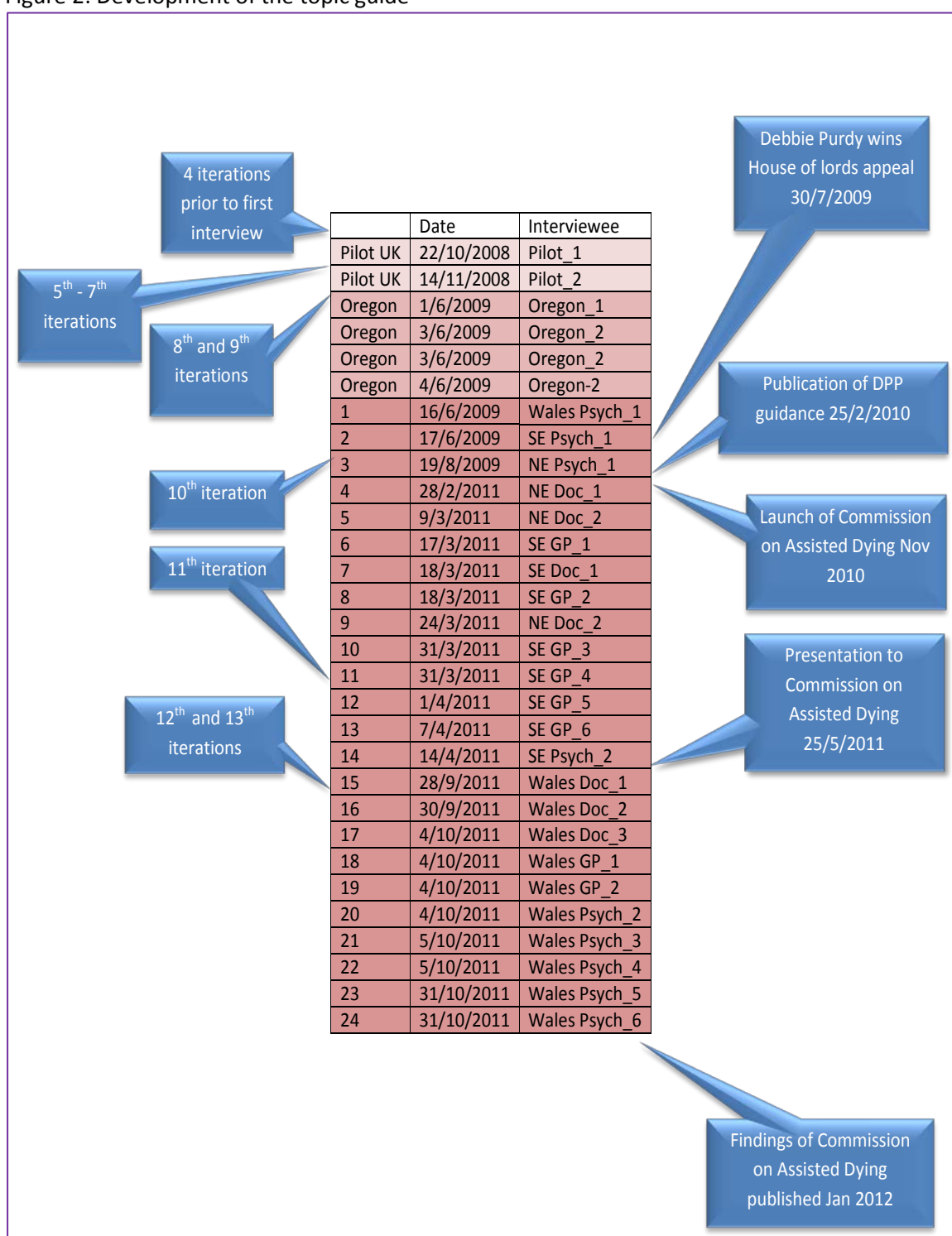
I initially drafted ideas for the topic guide on 16/9/2008. During the interview process I made 14 iterations of the guide, the last being on 21/9/2011 prior to my final interviews and at the point that I had decided upon my core category. This final draft of the topic guide emphasised and built on the section about knowing the patient and raised some specific questions to further explore this emerging category¹².

The diagram below (Figure 2) shows the relationship between the topic guide iterations, the interviews and some of the significant events that occurred during the data collection process.

¹¹ See Appendix 5: Summary of the Assisted Dying Bill 2005 given to research participants prior to interview

¹² See Appendix 6: Final topic guide

Figure 2: Development of the topic guide



3.6.5 The interview procedure

My study was based on a series of audiotaped individual in depth interviews with doctors. My aim in conducting the interviews was to gather rich data which accurately reflected the authentic perspectives and experiences of the participants. Although they emphasise the

grounding of analysis and theory in the data, Glaser and Strauss, Glaser, and Strauss and Corbin provide little detail on how to conduct a good 'grounded theory' interview beyond advising that it is inductive rather than hypothesis driven at the outset of data collection, moving toward a more deductive approach as the core category emerges. Charmaz (Charmaz, 2006) provides more guidance on the interview process in her chapter 'gathering rich data' which gives advice on approaches and example interview questions. Here she describes the 'intensive interview' as a 'directed conversation' where the interviewer 'is there to listen, to observe with sensitivity, and to encourage the person to respond'. She differentiates the interview from a conversation though, because sensitive or intimate topics might be explored in greater depth than etiquette would usually dictate. Charmaz sums up the role of the interviewer as helping 'the research participant to articulate his or her intentions and meanings', whilst emphasising the negotiation that occurs between interviewer and participant during the interview. Charmaz cautions against forcing the interview in certain directions through the use of overly directive questions or lines of questioning and advocates the development of self awareness in the process.

Kvale (Kvale, 1996) describes in detail the interview situation in qualitative research more broadly and defines the qualitative interview as 'a specific form of human interaction in which knowledge evolves through a dialogue'. He contrasts the qualitative interview with the anonymity of a survey questionnaire and the personal nature of a therapeutic interview. He emphasises the responsibility of the researcher to provide an atmosphere of trust in which the interviewee 'feels safe to talk freely about his or her experiences and feelings' whilst guarding the boundary beyond which is a therapeutic relationship. He also talks about the 'unwritten script' that is followed by both interviewer and interviewee who fulfil specific roles in the process.

Kvale provides 'quality criteria' for the qualitative interview comprising six points:

1. The extent of spontaneous, rich, specific, and relevant answers from the interviewee.
2. The shorter the interviewer's questions and the longer the subject's answers, the better.

3. The degree to which the interviewer follows up and clarifies the meanings of the relevant aspects of the answers.
4. The ideal interview is to a large scale interpreted throughout the interview.
5. The interviewer attempts to verify his or her interpretations of the subject's answers in the course of the interview.
6. The interview is 'self-communicating'-it is a story contained in itself that hardly requires extra descriptions and explanations

My training in medicine and particularly psychiatry had included training in interview skills such as building rapport, establishing trust, asking a range of question types dependent on the situation and being comfortable with silences. These skills however had been developed in a specific context: within a therapeutic relationship with patients and orientated toward the diagnosis and management of mental disorder. As Kvale points out, this relationship is different in nature and focus from the interviewer-interviewee relationship in a research setting and adapting my usual interview style to accommodate this new type of relationship and with doctors rather than patients was challenging.

Looking back over the interviews though, I noticed that I asked fewer questions and my contribution relative to the interviewees' became less as data collection progressed. I also relied less on the structure of the topic guide as the interviews progressed and as a result the interview content became richer and more diverse. I also engaged more in 'checking' and interpreting the meaning of what had been said *with* the interviewees, as I began to tentatively test microtheories. I also tentatively introduced my emergent theory in later interviews and worked with the interviewees to see whether the emergent theory reflected their own experience.

3.6.6 Coding and memoing: parallel procedures

Coding is the 'core process in classic grounded theory methodology' (Holton, 2007) and is intended first to *fracture* and then *reassemble* the data with the aim of raising the conceptual level of the analysis with the ultimate goal of generating theory which is grounded in the data.

Charmaz (Charmaz, 2006) defines coding as 'naming segments of data with a label that simultaneously categorises, summarises, and accounts for each piece of data'.

As grounded theory methodology has developed, different approaches to the coding process have been described. In 'classic' grounded theory (Glaser and Strauss, 1967) the process proceeds in two main stages: *substantial coding (open coding and selective coding)* and *theoretical coding*. To this process Strauss and Corbin added the intermediate stage of *axial coding* in which the researcher systematically goes through a process of 'relating concepts/categories to each other' (Strauss and Corbin, 1998) using an explicit 'coding paradigm' including *conditions, actions/interactions* and *consequences*. This approach has been criticised by Glaser, who sees this as an example of forcing the data and negating the emergence of category and theory from the data (Glaser, 1992).

Charmaz presents a flexible solution to the issue of whether or not to engage in axial coding by saying,

Axial coding provides a frame for researchers to apply. The frame may extend or limit your vision, depending on your subject matter and ability to tolerate ambiguity. Students who prefer to work to a preset structure will welcome having a frame. Those who prefer simple, flexible guidelines-and can tolerate ambiguity-do not need to do axial coding. They can follow the leads defined in their empirical materials (Charmaz, 2006).

In grounded theory methodology, the coding process is punctuated throughout by *memoing* in which the researcher pauses to 'stop coding and capture, in the moment, the conceptual ideas that they are finding' (Holton, 2007). Memos are used at every stage in the process from open coding to theory generation.

According to Glaser (Glaser, 1978), the writing of theoretical memos is the core stage in theory generation; it is the point at which the researcher theorises the relationships between codes during the coding process. Charmaz concurs that memo-writing is a pivotal step in the process between 'data collection and writing drafts of papers'. She says that 'when grounded theorists write memos, they stop and analyse their ideas about their codes and emerging categories in whatever way that occurs to them'. This approach a) prompts researchers to analyse their data

early, b) keeps researchers involved in the analysis and c) helps them to increase the level of abstraction.

The following sections describe in detail the process of coding and memoing, giving examples of each stage. The integrated process of coding and memoing that led to the emergence of the core category is also demonstrated in Appendix 9: Emergence of the core category.

3.6.6.1 Initial 'open' coding

According to Charmaz (Charmaz, 2006), the initial stages of coding are intended to explore the theoretical possibilities within the data and learn about 'what the research participants view as problematic' before coding becomes more selective and theory driven. Holton (Holton, 2007) advises that researchers do their own coding as this 'constantly stimulates conceptual ideas'. She warns that coding 'may feel very awkward at first, and the researcher may feel uncertain about labelling the codes, but this sense of uncertainty gradually subsides with continual efforts at analysis'.

In my study, the initial stages of coding involved detailed reading of the transcripts in conjunction with listening to the audio recordings of interviews and re-reading of my field notes. Open coding of my initial interviews yielded a large number of novel codes, for example in coding my first interview, over 60 new codes were generated which categorised over 160 pieces of data.

A table showing an example of open coding is shown in Appendix 7: Open coding example.

As coding progressed, the relationships between individual codes began to emerge and categories began to form. An example of this is given in Appendix 8: Emergence of categories example, using the same excerpt as shown in Appendix 7: Open coding example.

3.6.6.2 Early memos

Early memos commented on aspects of the coding process that raised questions or stood out as potentially interesting leads to follow. An example of an early memo refers to a comment made by a participant about mental capacity legislation being a way to help patients remain in control of their treatment:

Capacity assessment as a means of giving patient control: do many clinicians take this primarily patient centred view? How does it give patients control? Opportunity to discuss treatment?

The following memo refers to a comment by the same respondent when talking about assessing mental capacity for patients who have offered to be altruistic organ donors:

What is meant by ulterior motives? This phrase often signifies a less than honest agenda. Does the psychiatrist have a role in ascertaining the patient's 'agenda' and determining whether this is an acceptable one? Does this again feed into a judgement about values and the acceptability of decisions? What would be the ulterior motives for wanting to donate a kidney? Is donating a kidney for less than purely altruistic reasons likely to be damaging to self or others? Is there a protectionist agenda at work here? Does the doctor have a duty to stop the patient making decisions based on the work of the 'subconscious' or motivations that are hidden from them? Is the psychiatrist the right person to work out what these motivations are and decide if they are to be indulged or not?

As coding proceeded, one category began to emerge that related to many incidents in the data and to other codes. As shown in section 3.7 the conceptual category 'knowing the patient' was the core category upon which further sampling, coding and analysis was based. The core category was chosen after analysis of the 14th interview and thereafter coding was selective and focused on the concept of knowing the patient and its relationships.

3.6.6.3 Focused 'selective' coding

Focused coding 'begins only after the researcher has identified a potential core variable' and further data collection and coding 'is delimited to that which is relevant to the emerging conceptual framework' (Holton, 2007). Holton advises that once focused coding begins, the process of data collection and coding speeds up considerably and continues until 'the researcher has sufficiently elaborated and integrated the core variable, its properties, and its theoretical connections to other relevant categories'.

Once the core category 'knowing the patient' had emerged and been committed to, data collection proceeded with a focus on this concept and its relationships, and coding focused on elaborating on the concept of 'knowing the patient' and how this was related to other codes and categories in the data.

As the core category was emerging, so was the theoretical construct of knowing the patient as a contextualised phenomenon and further coding sought to further elaborate on the contextual factors that were related to knowing and getting to know.

3.6.6.4 Theoretical coding

As analysis progressed, codes became increasingly abstracted and theoretical. According to Holton,

...conceptual elaboration concludes when the relationships among individually elaborated concepts emerge through the identification and use of appropriate theoretical codes to achieve an integrated theoretical framework for the overall grounded theory (Holton, 2007)

Contextualised knowing emerged as the key theoretical code in my study which developed through further analysis of the concept of knowing the patient and its relationships.

Another example of a more limited theoretical code was 'interpersonal congruence' which described how capacity decisions are influenced by the 'fit' between the doctor and the patient and brought together three other conceptual codes: *beliefs and values*, *personality factors* and *empathy*. Later, *interpersonal congruence* became part of the dimension of *quality* in the process of *getting to know*.

3.6.6.5 Theoretical Memos

During data collection and analysis the way I wrote memos developed as the process progressed. Initially I wrote memos as annotations to my reading of the interview transcripts- they identified points of interest, formulated initial ideas and questions and formed early links between different areas in the data. Further into the process I began to write more overtly theoretical memos on emerging concepts which were abstracted from the data and often written when I was away from the data. These assisted me in defining and developing my core category. Once the core category was identified and I gathered and interrogated the data in a more theory driven way, I wrote memos that identified links and relationships within and between data which helped me to develop a model that explained how variations in the core category related to the approach to patient assessment.

Finally toward the end of the process of analysis when I was exploring and delineating the limits and conditions of my core category, I found that theoretical memos could also be generated through interaction with my supervisors. These discussions helped me to strengthen and refine the model and its relationships.

The example below shows a theoretical memo considering the idea that the way the doctor viewed the dying process might influence how they approach assessment of patients requesting physician assisted suicide.

20/5/2011: Societal views of the dying process

This theme came up in one of the pilot interviews-the idea that the option of assisted dying could interrupt the normal process of adaptation to the reality of death and the opportunity for some sort of psychological growth within that. In another interview (not analysed yet), this was rejected saying 'feck off with your redemption' Coded as 'physician assisted suicide and societal views of the dying process'

Initially I had coded this as 'Societal views of the dying process' but as the interviews progressed and this theme recurred I refined the code to describing only the doctors' personal views of the meaning of the dying process and found that this linked with their views on the legalisation of physician assisted suicide and the way they would approach assessment. Until this point, although I had considered the potential role of doctors' values in the process, this had been a rather vague and general sense of cultural and religious identity. This memo reflects the emergence of a deeper understanding of a more professionally aligned morality in which a value judgement was made about how the patient chose to navigate the process of dying.

Some memos written during early phases of the coding process posed questions about the data and generated *microtheories* to be proved or disproved through comparison with other data and through further data collection. The example below was written whilst coding one of the first interviews, and concerns the potential interrelationships of personal beliefs and values between the doctor and patient.

7/8/2009 Wales Psych_1 Balancing values and beliefs

This is interesting: balancing personal values and beliefs with the values and beliefs of the patient and trying to do the right thing by weighing these considerations in the balance. So it's not just the patient weighing the decision in the balance, it's also the doctor? Need to ask a bit more about this.

This sense of relativity was reflected in other data as the interviews and analysis progressed and developed into the emergent concept of 'fit' and informed the conceptualisation of mental capacity assessment as relational and contextual.

Later memos became more expansive and explanatory. The memo below was written in response to a comment from one of my supervisors about my idea of the importance of the doctor's individual perspective in the process of getting to know the patient. I had called this 'knowing the self in the process' but the discussion highlighted the potential difficulties with identifying this property as self knowledge. I re-examined my ideas and developed a descriptor which better encapsulated the data and allowed me to more accurately describe the conditions on which my core category was built:

22/12/2013 Frame of Reference

I think maybe what I'm trying to illustrate is that there were distinct perspectives that I could identify by category which did seem to have an impact on how the relationship was viewed and I think had the potential to inform the process of capacity assessment. Maybe it is a case of relabelling it as 'frame of reference' or 'perspective on the doctor-patient relationship' which then informs a sense of knowing rather than it being a true dimension of knowing e.g. a condition rather than an 'ingredient' per se.

3.6.6.6 Negative case analysis

According to Glaser and Strauss (Glaser and Strauss, 1967) one of the indicators of methodological rigour is evidence of the identification of negative cases and analysis of why these cases do not fit with emergent theory in order to produce a model which has greater explanatory power. The following provides an example of negative case analysis in this study. When analysing the data I found that the participants saw the issue of assessment of mental capacity assessment through different *frames of reference* which were categorised as *professional*, *personal* and *moral*. Most of those who had a moral frame of reference opposed the legalisation of assisted suicide mainly due to religious misgivings. One participant was an exception to this though-his frame of reference was moral but he supported legalisation of assisted suicide. On closer analysis of this interview, the participant had been trained in medical

ethics and law and thought that this background had strongly influenced his world and professional view. This initially negative case therefore gave further support to the emergent concept of knowing as a contextual phenomenon influenced by training background among other influences.

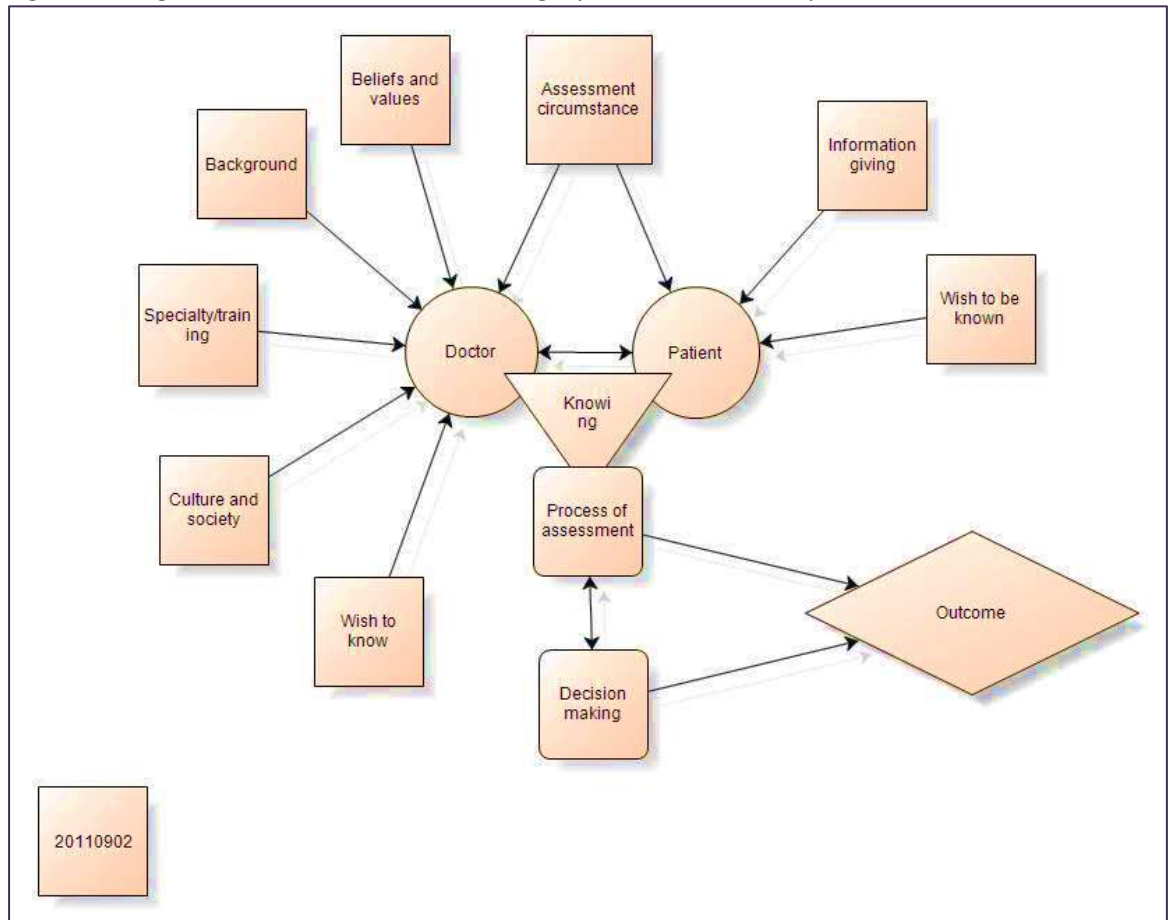
3.7 Emergence of the core category

The central concept of *Contextualised Knowing* developed from the core category 'knowing the patient' and other codes related to this category. The category 'knowing the patient' was identified as having potential importance via sensitising concepts in the initial literature search, was strengthened theoretically through the interviews in Oregon and then developed empirically through the process of data collection and constant comparative analysis.

During the study I documented my developing ideas in a number of ways. Firstly by making notes of ideas that were generated during supervision, secondly by recording my impressions of important areas emerging from each interview in the form of fieldnotes, thirdly by writing theoretical memos during the coding process and lastly by recording my developing thoughts and ideas in a reflective log. The table in Appendix 9: Emergence of the core category charts the development of the core category from the initial stages of the study through to the stages of focussed and theoretical coding.

Once the core category had emerged, I produced a diagrammatical memo (Figure 3) showing the place of knowing in the process and how this related to assessment and outcome. These interrelationships were refined as theoretical sampling and focussed coding progressed.

Figure 3: Diagrammatical memo of core category and its relationships



3.8 Emergence of a model of the relationship between knowing and decision making

Through further analysis of the relationship between knowing the patient and the way mental capacity decisions were made, a model emerged which explained much of the variation in the data. The model of a 'spectrum of knowing' demonstrates both graphically and narratively the relationship between two of the key conceptual areas in the data: knowing the patient and how capacity decisions are made. Integral to the model are the conditions in which this decision making process varies according to the way patients are known and the narrative exploration of the model provides an explanation for how a range of factors contribute to a sense of knowing via a process of getting to know.

A table showing how the model emerged through memos and the reflective log is presented in Appendix 10: Emergence of the model of the relationship between knowing and decision making.

These memos provided the basis of my final theoretical model of knowing as a contextual phenomenon, which influenced in a predictable way how capacity assessment was approached by the doctors in the sample according to their sense of knowing the patient.

3.9 Theoretical saturation

In grounded theory methodology, sampling proceeds theoretically as described in Section 3.6.3.4. According to this methodology, sampling then continues until the data has reached *theoretical saturation*, whereby according to Glaser and Strauss (Glaser and Strauss, 1967) 'categories and their properties are considered sufficiently dense and data collection no longer generates new leads'. Sample sizes are therefore not specified prior to recruitment, so the point of saturation is determined by reviewing analysis of existing data and recognising that recent interviews have not generated any new theoretical avenues needing to be explored further. According to Breckenridge (Breckenridge J and Jones D, 2009), saturation is more than 'mere descriptive redundancy' but the point at which the data has served theoretical development and is achieved when a theory has been generated which can 'cope with changing situations' and has 'temporal transferability'.

In my study, the 24 interviews generating the main data allowed for the emergence of the core category of knowing the patient, a detailed description of its development and relationships, and an explanatory model of the relationship between knowing and capacity decision making. As well as exploring the core category and emerging theoretical model with this sample, I also tested the emerging category and theory for 'fit' with other psychiatrists by presenting my emergent findings during various phases of development within my department and at conferences. I also sought feedback from my original sample as described in section 3.6.3.4 which validated my emergent theoretical model. In addition I sampled outside of the situation of interest and found a good fit with my emergent theory.

Putting all of these sources together I was satisfied that I had reached theoretical saturation to a sufficient level to present a credible substantive theory.

3.10 Summary of the interview data management strategy during the process of analysis

With my participants' consent, digital recordings of their interviews were made and later transcribed and presented in written format in Microsoft Word documents. I had previously transcribed the two pilot interviews myself but recordings of the main interviews were transcribed by a professional transcription company. The decision to use a transcription company was made due to the time involved in transcribing the interviews which were often long (the longest interview was 89 minutes, the shortest was 33 minutes, with mean interview length 63 minutes). The company chosen was used frequently by the University, had a robust confidentiality agreement in place and used a secure online system for sending audiofiles and downloading completed transcripts.

Once received, the electronic transcripts were stored on a secure drive and saved under a file name which did not contain the respondent's name.

After transcription, the written transcripts were checked for accuracy by concurrently reading carefully through them whilst listening to the audiotaped interviews. Personally identifying information was then removed and transcripts were uploaded to the qualitative analysis software programme Nvivo (QSR International, 2012) which was used to store the interviews, record the reflective log and record and organise a number of field notes and memos.

Nvivo was used to support open coding of the first 14 interviews, after which point a core category was identified and I proceeded with more focused coding. At this transition point I felt that, whilst Nvivo had proved very helpful in generating and hierarchically organising numerous codes from multiple interviews, the number of codes and the way that the interface presented this information began to obscure further analysis of the core category and its relationships.

The data had been through a necessary stage of fracturing and dis-integration, but now there was a need to reintegrate the codes with the data to proceed meaningfully with the constant

comparative method at the next theoretical level. To develop the core category and explanatory model, I needed to analyse the relationships between the core category and the contextual material in the interviews. At this stage, I decided to proceed by engaging with the data more directly using the transcripts both electronically and in printed copy, in conjunction with repeated listening to the interviews and re-reading of my field notes.

Once the core category and its key relationships had emerged, I went back through all of the preceding interviews to verify these relationships and actively look for negative cases and alternate conditions. In doing this I developed lines of further enquiry which I organised under headings using a Microsoft Word document and illustrated using sections of text which I annotated and then created memos to guide further enquiry. I found that the editing and review functions of Microsoft Word (e.g. comments) were sufficient to allow me to do this whilst preserving an intimate relationship with the data.

In addition to using word processing and data management software to assist organisation and analysis of the data, I used other technologies in the process of analysis. I found that the online app/programme 'Evernote' was helpful in recording and storing memos as it allowed for chronological logging of memos. Evernote will store information in a number of formats including voice recordings, is available on smartphones and will synchronise across devices so a memo entered onto the phone will then be available for later consideration on the desktop and easily linked to further useful data. I found that during more 'creative' phases of the study, this functionality surpassed Nvivo in utility and flexibility. I did find however, that ultimately there was no substitute for immersion in the written transcripts on paper and annotating directly onto the transcripts and creating memos using 'post it' notes during analytical phases. I found that my own handwriting on the transcripts triggered the process of linking to other data and codes in a way which had no electronic equal.

3.11 Respondent validation

In grounded theory methodology, member or respondent validation is a continuous process throughout the study in which the researcher checks the fit of emergent theory with theoretically sampled participants (Elliott, 2005).

Once my core category had emerged and I began to tentatively develop a theory about the relationship between knowing the patient and decision making, I began to ask my respondents specifically about this relationship within the interviews, for example:

INT One thing that I've been picking up in a lot of the similar conversations that I've been having and I think it does reflect on this idea of your doctor doing assessment versus an "expert", is the issue of how knowing the patient or having a pre-existing relationship with the patient would impact on the process. Do you have a sense of what that might be like in terms of whether you know the patient already or whether they are a new patient to you asking for this?

RES I think it might have an effect. Even with your own patients there are some you know better than others just by chance in terms of perhaps the number of times you've seen them or they're more open. Quite a few patients you might actually see a lot but you don't really know them, they don't show much of themselves. I think that that might even be a hindrance in some ways. It complicates issues. I think you would probably get to know someone if you spent the time well enough to understand what they're going through... a tricky one. I know some patients very, very well. If they were to come up with those sort of ideas and it was legal I'm not sure how it would help me much except I might be sympathetic more to them maybe because I know them and therefore I know whether they're *compos mentis* or not and if they're saying this then perhaps it's more credible. But equally I'm sure someone from outside could get that picture with a bit of time with a patient. I think some doctors would probably like that independent view rather than feel that they perhaps might be biased in one way because they know the patient very well. [Wales Doc_1]

In their proposed criteria for a quality grounded theory study, and in contrast to Elliott, Corbin and Strauss (Corbin, 2008) ask 'Do the findings resonate with the experience of both the professionals for whom the research was intended and the participants who took part in the study?' and describe this quality as 'fit'.

I therefore sought further validation of my emergent findings. I did this in two ways. Firstly I presented my findings as they developed at several conferences and meetings both internal and external to my institution and considered my findings in light of the feedback I received. Secondly I sought feedback from my research participants directly by writing to them and

sending them a PDF of a poster I had presented at a conference showing a summary of my main findings.

The response to this request for feedback was limited, but was positive and reinforced my emergent theoretical model.

A summary of the feedback I received is shown in Table 5.

Table 5: Respondent validation, summary of participant feedback

Respondent	Comment
1	Xxx said it seems to fit with his thinking and has no other comments. And well done!
2	Well done on producing such a thorough piece of work.
3	The poster is very clear and the conclusions make sense. My own view would be that the procedural element of capacity assessment would be fairly standard but that the degree to which we would rely on the intuitive or empathic elements would vary in the way that you describe.
4	I think your concept of a sense of knowing is a very important addition to rational debate and policy making about this subject. In a wider context, I think your work brings some academic rigour to the fallacy of thinking that we can turn what are inevitably somewhat subjective decisions into objective ones by applying tests that ultimately depend on the interpretation of words.
5	I have nothing to contribute that would contradict your thesis

3.12 Situating the findings within other sources of knowledge

In grounded theory methodology the study findings once developed are situated within a conceptual framework of other sources of knowledge in the substantive area. In this study I have situated my findings not only within the literature on knowing the patient and decision making in healthcare contexts (Chapter 6) but also within other research I have conducted on physician assisted suicide (Chapter 5). In this way I have shown how my findings are situated within what is known about my substantive area of research but also in the literature relating to my emergent theory. In these two chapters I examine my findings in relation to these information sources and discuss not only how they ‘fit’ within what is already known in these areas but also how my findings extend these literatures.

3.13 Methodological limitations

As part of an approach emphasising methodological rigour, a clear account of potential limitations allow the reader to assess the credibility of the study procedures and findings. In the

following sections I will present areas in which my methodological approach and chosen methods introduce potential limitations to the study.

3.13.1 Study timeframe

In section 3.5.3 I discussed as a possible methodological advantage how two periods of maternity leave allowed me to 'step back' from the study. My PhD studies were conducted part time, punctuated by two eight month periods of maternity leave. This has resulted in a seven year period from registering for the PhD to completion of the thesis. As presented in section 2.2 there has been considerable development of the legal landscape both nationally and internationally over this time period reflecting a cultural shift toward a more prominent public debate on the value of quality vs quality of life and the increasingly prominent position of autonomy and personal choice in medicine.

The majority of the data for the main study in this thesis were collected between 2009 and 2011. It is possible that were this data collected more recently, the rapid development of the assisted dying debate would have been reflected the data and therefore the findings. The procedure of respondent validation however took place in 2014, once analysis of all of the data presented in this thesis had been completed. That the respondents considered the findings still valid is likely to mitigate the potential risk that the timeframe of the study renders the findings less valid in the current social and legal context, particularly since at the time of completion, there has been no substantive change to the legal context nationally.

3.13.2 Interview procedures

As presented in section 3.6.3.3, the majority of the interviews with doctors took place face to face, though for pragmatic reasons it was necessary to conduct some interviews by telephone. Though efforts were made to make sure that those participating in telephone interviews were as well prepared as those participating in face to face interviews, and the setting was as far as possible conducive to the collection of good quality data, it is possible that the telephone interviews yielded data that was less high quality than the face to face interviews. On reviewing the transcripts and audio recordings of the telephone interviews compared with the face to face

interviews, the main differences evident were the slightly shorter average length of the telephone interviews (mainly requested by the interviewees because of their own time constraints), and there was a tendency toward a less smooth conversational interaction. This study did not utilise discourse analysis therefore more detailed comparison of the transactional quality was not possible.

3.13.3 Supervisory roles and personal affiliations.

As presented in section 3.5.5.1, I was mindful of my own values and beliefs and their potential to impact upon my approach to the study and interpretation of the data, but it is important to acknowledge potential influences on my personal position during the process of conducting this study.

My first PhD supervisor, Prof Matthew Hotopf, has previously voiced his concern about the legalisation of assisted suicide for the terminally ill, and this position has been declared in publications related to physician assisted suicide e.g. (Lee et al., 2009). He has also declared, though, that he has no religious views that prohibit assisted suicide (Hotopf et al., 2011b).

My second supervisor, Dr Theresa Wiseman, has never stated a position publically on whether assisted suicide should be legalised. In a paper related to this thesis, co-authored with both supervisors, Dr Wiseman did not declare any relevant conflict of interest (Price et al., 2014).

Neither Prof Hotopf, Dr Wiseman, nor I have affiliation to or membership of an organisation representing a position in the assisted dying debate.

The Royal College of Psychiatrists, of which I am a member, has recently stated a neutral position on legalisation of assisted suicide for the terminally ill.

3.13.4 Ethical permissions

As introduced in section 3.12 and presented in detail in section 5.2.3, I have compared the findings of my study of doctors in England and Wales with the findings from analysis of interviews with professionals in Oregon involved with the assessment of terminally ill adults requesting physician assisted suicide. Grounded theory methodology encourages the consideration of data that assists the building of theory, but it is not always possible at the

outset of a grounded theory study to know which data will be relevant to the eventual findings. The ethical permission for this study therefore did not specifically include the interviews with the Oregon professionals.

As stated in section 5.2.3, however, consent was granted by the interviewees to audiotape and analyse the interviews as part of my PhD studies. The lack of specific ethical approval for this portion of the study did however present a dilemma as to whether to include analysis of these data in the thesis. In making the decision to include the data from the Oregon professionals I reviewed the consent that had been given, discussing this with my supervisors, and was satisfied that it was to the same ethical standards as that given for the main interview study. In drafting the manuscript I was careful to maintain the anonymity of the participants when quoting excerpts from interviews.

3.13.5 Experience in grounded theory research

Throughout this chapter I have described in detail the methodological approach and processes that underpin this study. At the outset of my PhD studies my research experience was mainly in epidemiological methods, but as described in section 3.5.1, a grounded theory approach was selected as most appropriate to the research question.

As I will further discuss in section 7.2.1, this study was not only a process of discovery in the substantive area of investigation but also a learning process on the theory and application of a grounded theory approach. As an apprentice, I maintained a focus on methodological rigour throughout the process of conducting and writing up the study, regularly referred to texts and methodological papers on grounded theory methodology and checked frequently that my approach was consistent with a rigorous methodological approach. Whilst this attention to detail was a potential strength in terms of methodological rigour, it may also be viewed as a potential constraint on the creative process that is also integral to grounded theory methodology. A more experienced grounded theory researcher may have taken more creative or original methodological decisions which in turn may have yielded a more mature interpretation of the data gathered.

3.14 Summary

In this chapter I have described step by step the development of this study from theoretical underpinnings through to a detailed explanation of the procedures used in conducting this study, culminating in the production of a substantive theoretical model that explains much of the variation in the data.

My chosen methodology, a grounded theory approach, employed a continuous interplay between sampling, data collection and constant comparative analysis with the aim of generating findings fully grounded in the data to produce a credible theoretical model.

From an initial broad research question addressing how doctors in England and Wales would conceptualise and assess mental capacity for terminally ill adults requesting physician assisted suicide, the core category of 'contextualised knowing' emerged from which a model of the relationship between the doctors' ways of knowing the patient and their approach to assessment of capacity developed.

4 Findings: Contextualised Knowing in Assessment of Mental Capacity for Terminally Ill People Requesting Physician Assisted Suicide

In this chapter I will present the main empirical findings of this thesis. The presented findings are initially descriptive then progress in analytical depth and abstraction toward an explanatory model which accounts for much of the variation in the data.

4.1 Introduction

In chapter three I described how the core category ‘knowing’ emerged and developed. In this chapter I will explore the emergent concept of ‘contextualised knowing’ and examine how this concept impacts upon the situation of assessment of capacity to request physician assisted suicide.

According to Glaser, the core category is the main theme that accounts for most of the variation in behaviour within the problematic situation (Glaser, 1978). It must be central and relate meaningfully to as many other categories as possible, it must occur frequently in the data and must have explanatory power.

In this chapter I will firstly show how individual contextual factors informed the doctors’ approach to capacity assessment; I will proceed to explore the process of ‘getting to know’, a process which leads to a sense of ‘knowing the patient’. I will then go on to demonstrate how this sense of knowing might impact upon the capacity determination process by presenting a model of a *spectrum of knowing* and show how the position of the doctor-patient relationship on this spectrum may have important consequences for the process of mental capacity assessment.

In all of the interviews, a sense of knowing emerged as an important concept when considering the approach to, and process of, capacity assessment. This was present both when doctors described capacity assessments that had been done already in clinical practice and when they thought more hypothetically about capacity assessments for patients requesting physician assisted suicide.

The findings showed that 'knowing the patient' in this situation existed on multiple levels and was both relational and contextualised. It emerged as a phenomenon which went beyond the immediate doctor-patient interaction, encompassing a complex and interrelated set of factors which together resulted in a sense of knowing unique to each doctor-patient relationship.

The doctors in the sample brought their own context or frame of reference to their sense of knowing which encompassed a broad range of elements. These elements included their personal views on the permissibility of physician assisted suicide and their perspectives on dying and the significance of a wish for hastened death, which informed their interpretation of the meaning behind a request for physician assisted suicide.

In addition to the perspectives held on the issues described above, the doctors' interpretation of capacity assessment for assisted suicide was viewed from either a 'professional', 'personal' or 'moral' perspective. These individual perspectives were informed by the doctors' values and beliefs, how they saw their role in the process of capacity assessment and how they envisaged the process might impact upon them personally.

The doctors' perspectives on the process of mental capacity assessment encompassed not just their ideas of how they as individuals interacted with the situation, but also how they perceived themselves as members of overlapping communities. The professional, personal and moral dimensions of their personal perspectives were interwoven with their views on physician assisted suicide but informed by how they perceived their involvement in the process might be seen by the communities in which they existed. These communities ranged from the geographical to the wider professional and social through to the microcosm of their clinical teams.

The doctors also identified factors that might be brought by the *patient* to the interaction which would impact on their ability to gain a sense of knowing that patient. Like the doctors, this would include their culture, values and beliefs, but also their 'wish to be known' and with that, the amount and quality of information that they were willing to bring to the interaction in order to build a relationship.

Conceptualisations of mental capacity for physician assisted suicide varied within the data. Professional group and views on legalisation of assisted suicide appeared to inform this conceptualisation; in particular whether capacity would be presumed and if it would be construed according to the framework of the Mental Capacity Act 2005. Mental capacity assessment for physician assisted suicide was consistently seen as a 'formal' process but the way this process would be approached was not consistent. Those who were in favour of assisted suicide leaned toward a presumption of capacity whilst those not in favour leaned toward a non-presumption, although most of the psychiatrists stated that they would both presume capacity and use the framework of the Mental Capacity Act irrespective of their views on physician assisted suicide.

With these contexts in mind, a sense of knowing the patient was consistently identified as key to the process of assessment of mental capacity. In order to reach a sense of 'knowing the patient' a process of 'getting to know' was described, comprising three interrelated elements: 1) Temporality (the importance of time in gaining a sense of knowing), 2) Dimensionality (developing a sense of knowing through experiencing the patient in a number of different dimensions both personally and through others) and 3) Quality (being able to interact with the patient in a meaningful way in order to generate a sense of knowing that is personally satisfying).

Whilst detailed data emerged on 'getting to know', defining the state of 'knowing' proved more elusive. The conditions of knowing varied between professional groups, with general practitioners having a sense of knowing the patient as part of their wider family and community system, while the specialists talked more about knowing individuals.

The findings showed that whilst knowing was thought to be central to the capacity determination process, there were perceived risks associated with knowing the patient in terms of negatively impacting upon objectivity in capacity assessment, a risk which was seen as important to minimise or mitigate.

From within the data a ***spectrum of knowing*** emerged. The position of the specific doctor/patient relationship on this spectrum appeared to influence the internal model that the doctor might use to assess capacity. The findings showed that when the patient is 'not known' or 'not known well', the doctors favoured a protocol driven assessment framework, potentially involving the use of checklists and structured processes. As the patient was better 'known' the doctors moved toward a more pragmatic 'gut feeling' based assessment which was looser in structure with decision making more implicit. However if the patient was known 'very well' or 'too well' the doctors moved consciously toward a more protocol driven assessment in order to negate their perceived sense that their own views and values might be influencing the process.

In summary, the way a patient is 'known' by the doctor is complex and central to the way in which capacity assessment is approached. A wide range of individually interpreted influences were funnelled into the proposed capacity assessment process with the potential for impact upon how these capacity assessments are carried out. This may have important implications for the process of capacity assessment for patients requesting physician assisted suicide. The following sections explore these concepts and processes in more detail.

4.2 Section 1: Defining the context

4.2.1 Views on legalisation of physician assisted suicide

Within the sample, a range of views on the legalisation of physician assisted suicide were represented, from strong support to strong opposition, although more stated themselves to be opposed to, than in support of, legalisation.

Table 6 shows the participants' views on the legalisation of physician assisted suicide by professional group and by region.

The general practitioners were the group most in favour of physician assisted suicide and the 'other doctors' group were most against. The 'other doctors' group comprised two palliative care physicians, three surgeons and two oncologists. Of the three surgeons, one was in favour

of legalisation, one was neutral and one was against. Both of the oncologists and both of the palliative care physicians were opposed to legalisation.

By region, the south east England doctors were most in favour of legalisation but the majority of this sample (6/9) comprised general practitioners.

Table 6: Views on the legalisation of physician assisted suicide by professional group and by geographical region

	In favour (%)	Neutral/no strong opinion (%)	Against (%)	Total
By profession				
Psychiatrists	2 (22)	3 (33)	4 (44)	9
General Practitioners	5 (63)	2 (25)	1 (13)	8
Other doctors	1 (14)	1 (14)	5 (72)	7
By region				
North of England	1 (25)	0	3 (75)	4
South of England	6 (67)	1 (11)	2 (22)	9
Wales	1 (9)	5 (45)	5 (45)	11
Total	8 (33)	6 (25)	10 (42)	24

4.2.2 Personal values and experience in relation to terminal illness

In discussion of mental capacity assessment for terminally ill adults requesting physician assisted suicide, a number of the doctors offered their personal views on the human response to approaching the end of life and the meaning of suffering. These views appeared to be informed by various beliefs and experiences, from the professional to the personal, were entwined with their views on the legalisation of physician assisted suicide and informed their approach to assessment of capacity for physician assisted suicide.

4.2.2.1 Response to terminal illness and the dying process

The findings showed a variety of ideas about the normative response to terminal illness. A number of doctors thought that the ‘normal’ human response to impending death was to wish to remain alive for as long as possible.

...it’s unnatural, deeply unnatural to want one’s own end. Most human beings spend life trying to avoid that, not wanting to. [NE Doc_2]

One doctor (a surgeon) further described the ‘natural’ human state as a wish for immortality, with other states being potentially pathological,

I don’t think anybody at all wishes to shorten their life. I don’t at the moment really believe that. I’m willing to accept it on the emotional level. And I think more that there is possibly a connection in the amygdala – I don’t know where it is, but let’s say there is a neuronal connection in the amygdala saying, ‘It’s time for the end of your life.’ Then it would be possible to take a knife and actually just cut that connection, and that would then be destroyed, and the person would then regain the wish to remain immortal. Which I kind of think is possibly the underlying, natural condition. [SE Doc_1]

A personal endorsement of the wish to remain alive in the face of death was stated by some, where living until the end was seen as brave, making the most of precious time and living for others. One GP who identified herself as religious and opposed to physician assisted suicide described her experience of working with young adults with cancer,

But there was no talk about assisted dying. They wanted to live, for every moment that they could. And I've remembered all of those individuals because their strength was amazing [SE GP_5]

and an oncologist, also opposed to physician assisted suicide, talked about his experience of working with young women with cancer, and their wanting to live on as a selfless act,

Bear in mind I only treat breast cancer patients and they are obviously women, mainly, and they're often quite motivated to stay alive as long as possible, children, husbands to look after and things...[Wales Doc_1]

The doctors who identified themselves as caring frequently for the dying especially the palliative care professionals described the process of dying as a potential opportunity for personal development once the barriers of fear and negative anticipation had been traversed. They saw physician assisted suicide as a potentially wasted opportunity to undergo this developmental phase because it might curtail the 'natural process of adjustment' that can occur toward the end of life.

One doctor not only described this in relation to individuals but also to how she believed the legalisation of physician assisted suicide might impact on society's response to the dying process,

There's something about the presence of assisted dying as a real option unless there's a sufficiently long... I could just see it really becoming quite complicated in terms of being able to work through the very natural process of adjustment. And whether it comes to acceptance, or however you frame it, the very natural process that people travel through as they get their heads round the fact that the time left to them is very short, and what matters most, and the things they need to do, all that process... There's something about the human mind where my fear would be that if there was an easy opt out button people might become, or the general ethos of society might become very averse to that sense of... I'm trying to think what to call it. I want to call it growth through suffering but that sounds a bit grim doesn't it? [NE Doc_2]

This conceptualisation of dying as an opportunity for personal growth appeared to influence several doctors' thinking about mental capacity assessment for physician assisted suicide because their ideas about weighing the decision in the balance took into account this potential for growth, where patients who made the decision to 'opt out' of that process were missing or being denied this opportunity through a sense of fear, not feeling able to bear the emotional burden of the process or working within a framework of immediate problem solving as opposed to more future focused coping.

One doctor, who self identified as strongly in favour of physician assisted suicide explicitly rejected this model of growth potential however, and strongly supported the idea that this was an imposition of personal values upon the decision making process. To those who see dying as a time of personal growth he said,

Fleck off with your redemption. You've got no right to impose...no one's got any right to impose their view of a correct life journey onto somebody else, and if someone says it would be so wrong for them to turn round and be a burden that actually they would rather be dead, it's not for me to say, 'Oh, no, you need to learn a bit of humility, you need to...' Actually no, if you don't want to do it, you don't want to do it. Die by your own likes. There you go. [SE GP_6]

4.2.2.2 Individual interpretations of the meaning of a request for physician assisted suicide

The findings showed that a request for physician assisted suicide was interpreted in a range of ways and that the interpretation depended on whether or not it was seen as a potentially *rational* choice in response to the circumstances, how mental disorder was seen to potentially impact on decision making and the personal impact of death and suffering in professional and private life.

4.2.2.2.1 The perceived relationship between rationality and mental capacity to request for physician assisted suicide

The meaning of a request for physician assisted suicide in terminally ill people was interpreted in various ways. Some felt that this could be a rational response to the circumstances,

...if I'm happy that this is the decision made in the rational way, with no influences which shouldn't be there, it's fine. [SE GP_1]

whilst others rejected the wish to die per se as a rational choice,

People have told me that there is a state worse than death, and I've never believed them, really. I've never really believed them. And I've tried to get them to explain to me what they mean, and each argument they've put forward to me I've tended to dismiss, actually. [SE Doc_1]

When asked how a capacitous decision for physician assisted suicide would be defined, most of the doctors talked about the decision being *rational*,

...it is to ascertain whether the person is capable to make a rational, weighed decision about anything in their own life, about anything in life, whether this person is capable and it's not influenced by mental disability, physical illness, mental illness, learning disability, that's what it is. [SE GP_1]

Those who considered physician assisted suicide as a rational response to terminal illness differentiated it from suicide for other reasons e.g.

Well, obviously, a huge number are mentally ill and it's incredibly common amongst people who are mentally ill, to try and kill themselves. People who are depressed, people who have schizophrenia, it's incredibly common. But, no, I think people who have very distressing neurodegenerative disorders of different sorts, or people following serious accidents and so forth, do sometimes make a rational decision. [SE Psych_1]

4.2.2.2.2 The perceived impact of mental disorder on mental capacity to request assisted suicide.

Mental disorder was identified specifically as having the potential to influence an individual's mental capacity to request physician assisted suicide and three disorders were identified specifically: psychosis, personality disorder and depression. Of the three, psychosis was felt to be fairly easy to identify and assess, with psychotic patients thought most likely to lack capacity. People with personality disorder were identified as a potentially difficult group to assess because their request for physician assisted suicide might be a reflection of their way of communicating distress, that if granted might represent a failure to correctly interpret and manage this distress,

Borderline personality disorder patients are always the most tricky for everything in lots of ways and it's just not as clear cut. So if you had a person who had psychosis who said they wanted to die because the devil was living in their stomach, that is such an obvious thing. They've got this really delusional belief, that's why they want to die; they're not in their right mind. Someone who is borderline personality

disorder can come across as very able and very well...The obviousness of their incapacity is much less obvious than it is with someone with schizophrenia. [Wales Psych_3]

I've got a patient with recurrent, or resistant depression who probably has personality disorder on the background as well, who comes in and has asked me if I would prescribe something which she could kill herself with. I think this is more to do with her personality disorder and her way of trying to relate to me. [SE GP_4]

Whilst depression was identified as a factor potentially impacting on capacity to request physician assisted suicide, there was a range of interpretations of the relationship between depression, terminal illness and requests for physician assisted suicide. For some, depression was seen as a normal response to terminal illness which should only be considered as a significant factor impacting upon mental capacity if severe. Others, who typically identified desire for hastened death as a potential marker for mental illness in the terminally ill, appeared to have a lower threshold for depression impacting on capacity, with the appropriate response being treatment aimed at ameliorating the desire for death,

The problem is that many of our patients have undiagnosed depression and what's the cardinal symptom of depression, that you end your life. So how do you disentangle that?...[Wales Doc_2]

Some of the doctors interpreted a request for physician assisted suicide primarily as a 'signal of distress' triggering a search for the cause. Possible sources of distress were identified including fear of future suffering and pain, not wishing to be a burden on others, finding a way of exerting control over the future, or a strategy for making the present situation feel more bearable.

Among the psychiatrists in the sample there was also a range of views regarding the impact of depression on capacity and this again was informed by views on the acceptability of assisted suicide. The psychiatrists expressing a view in opposition to physician assisted suicide saw depression as a risk factor for making an inappropriate decision to end their life, and the identification of depression as an opportunity to start treatment with the aim of delaying or reversing the decision,

Mood disorder which produces negative thoughts about self, treatment possibilities, past regrets and present and future hopelessness (all of which may respond to treatment) would leave a patient open to the risk of making a decision to end their life at a time when they were articulate enough to manage an interview but still depressed. [NE Psych_1]

and those expressing a view in favour of physician assisted suicide tending to see the request as understandable and whilst wanting to attempt to treat depression and more severe mental disorder, would not see ongoing depression as a reason to prevent the person from accessing assisted suicide,

I would suggest an antidepressant if they'd already been on it and it hadn't really made a difference in this I would say, 'Well, I see it as that is quite an understandable place to be in for some people.' I would want to make sure they weren't psychotic and all that kind of stuff [Wales Psych_3]

4.2.2.2.3 The perceived impact of personal experience on interpretations of the meaning of a request for assisted suicide

The findings showed that personal experiences might have a bearing on the doctors' responses to patients requesting physician assisted suicide, either by being reminded of previous patients in similar circumstances, or responding emotionally based on personal grief or loss,

Of course, if you're at the bedside of somebody you've also got the fact of your own emotional traumas with dealing with the increasing loss of a loved one, whoever it is and that colours your emotional reaction, which may not colour their emotional reaction. So what people see when they observe dying can be very, very traumatic and it's partly traumatic because it's traumatic but it's partly traumatic because it's coloured by those intense emotions of somebody you love and losing them. [Wales Doc_1]

Some thought that these experiences might have an effect on how they approached an assessment and potentially impact on their threshold for determining mental capacity, for example one doctor talked about how much 'leeway' might be given in an assessment depending on what emotional response they generated for the doctor,

So much communication is non-verbal and we may not always be aware of our own "gut" responses to people, e.g. those who remind us of people in our previous or professional lives, we may be subtly influenced in how much "leeway" we give some people and not others in our assessment. [NE Psych_1]

4.2.3 The perspective of the doctor in the process of mental capacity assessment

4.2.3.1.1 Individual perspectives

Differing individual perspectives were demonstrated when the doctors talked about assessment of capacity for physician assisted suicide. Within the data there appeared to be three main individual perspectives –‘professional’, ‘personal’ and ‘moral’. These were not necessarily mutually exclusive, although for each doctor there did appear to be a dominant frame of reference which guided their approach to mental capacity assessment.

4.2.3.1.1.1 Professional perspective

Those who described their capacity assessment predominantly from a professional perspective talked about their *skills* in relation to the situation being discussed. Their approach to assessment was present and situation focused. They emphasised their professional experience, with their apparent sense of ‘self’ in the decision making process being minimal. The language they used when describing capacity decision making was generally technical and process orientated:

I’m quite logical and need evidence to be able to make a professional opinion [SE GP_2]

Those with a ‘professional’ perspective described their role primarily in terms of ‘professional duty’ to the patient. They did not see a personal or moral dimension to their decision making as long as the correct professional processes had been followed,

...but I personally don’t feel any moral part of that decision. I feel as though I’m employed by the state to perform a function and I do it, hopefully with a degree of compassion and also with efficiency, or whatever the adjectives are you want to use. And I think, in the same way because I try to offer a very patient centred and a very individualised form of general practice, I would very much see my job as trying to help the person come to the best decision they can come to. So I wouldn’t feel any personal judgement or morality, for me as a human, I would just see my role as enabling the person to come to their own decision as best was possible. [SE GP_2]

I think if you’ve gone with the best of intentions, and you’re competent within that area that you’re supposed to be working, and when you’ve been uncertain or unclear you’ve tried to clarify something, and you’ve probably erred on the side of caution when you’re uncertain, then that’s probably the best you can do. [SE GP_4]

For this group of doctors mental capacity assessment was viewed as a skills based task, where a good quality assessment could be achieved with the necessary professional expertise which was either inherent to their professional role or could be gained with the appropriate experience and training.

The group with this individual perspective comprised mostly GPs and most expressed views that were supportive of physician assisted suicide.

4.2.3.1.1.2 Personal perspective

Those who described a primarily personal perspective were explicit about their personal beliefs and values and how these might impact upon their decision making. They frequently described patients and their difficulties in language that was relative to themselves and focused on the emotional aspects of their relationships with their patients,

I just had a patient the other day who has got Huntington's, which is a particularly awful illness and we've just found that out and he's still got some capacity and if he were to turn around and say, 'You know what, I've seen what this does, I've got my wits about me now, I do not want to end up like him, I'm going to ask for that now', I would feel, 'You know what, I would do the same.' And I think that's coming from thinking I would want that for me, I would want that for my mum or my dad...
[Wales Psych_3]

They felt that objectivity in decision making was less achievable than those with a more 'professional' perspective because of the potential impact of their personal beliefs upon the decision making process,

I think it would always be a very grey area and subjective decision. I mean I'm sure legal processes would cause it to be separated into little boxes of statements and yes or no answers, but in practice that would be putting a bit of a sort of veneer of objectivity on something that was really fairly subjective. [NE Doc_1]

Some of those who described their personal perspectives in the decision making process expressed their doubt not only about their own objectivity but also the possibility of any clinician achieving objectivity,

There really is going to be huge variability, not because we're bad but for all the complex reasons we've talked about. People have different beliefs, different stances, different starting points. It's almost impossible as a subject area to be completely objective about...and to imagine there's this pool of very cool, hard

headed, objective people out there who can do these capacity assessments in a very consistent fair way I think may be in the realms of fantasy. [NE Doc_2]

The doctors taking a personal perspective expressed views on physician assisted suicide that both supported and opposed legalisation and doctors from all three of the professional groups took this perspective.

4.2.3.1.1.3 Moral perspective

Those who took a moral perspective talked about making capacity decisions that were 'right' or 'wrong'. The morality was often described in religious or spiritual terms e.g.

'...the other issue that comes along with that is someone's own belief I think and their faith, and being a Muslim I have a very strong faith in preserving life, so that comes with it as well'. [Wales Psych_1]

The moral perspective for some was more philosophical however,

'...I think what I'm saying... I'll just...say, you know, to have this discussion, actually what I'm ending up talking about is the basis of my beliefs and my life'. [SE Doc_1]

Decisions had a future focus for the decision maker and personal consequences outside of the immediate ramifications of the decision being made. One interviewee, for example who defined themselves as a religious Roman Catholic, ultimately anticipated judgement by God,

Because I believe that ultimately I have to answer for everything I do, and you know, sanctioning the taking of life isn't something that I feel I can...I'm going to have to stand up and answer for what I do one day, it's not something that I think is right. [SE GP_5]

Some who described a moral perspective talked about the anticipation of guilt if they made what they might later perceive as the 'wrong' decision, whilst others felt uncomfortable about being part of the process at all based on an anticipation of moral discomfort,

The biggest consideration would be the sleepless nights. It wouldn't be nice. So that would be my worry. [Wales Psych_4]

As with those expressing a 'personal' perspective, all three groups of doctors were represented. With the exception of one doctor [SE GP_3] who made explicit reference to his moral standpoint in relation to his support of the legalisation of physician assisted suicide, the

doctors with a moral perspective expressed their opposition to the legalisation of physician assisted suicide.

4.2.3.1.2 Community perspectives

In addition to the individual perspectives, other perspectives reflected a sense of membership within a number of overlapping communities. These included the geographical community, the social and cultural (including religious) community, the professional community and the clinical team. How the doctors viewed themselves within these communities appeared to be related to how they perceived their role in capacity assessment for physician assisted suicide and the consequences that their involvement might have for themselves and these communities,

It would potentially affect your relations with other people, both in a medical community and in the wider community. I think it would be very naive to go into that work without having fully thought about the possible implications of it. [NE Doc_1]

Overall, those doctors who considered the impact of their involvement in physician assisted suicide upon their communities were more cautious about this involvement and were concerned about a negative impact on themselves and those around them.

4.2.3.1.2.1 Geographical community

Many of the doctors described the geographical communities in which they practiced. They described them in terms of the socioeconomic context, the types of people living there and their history and development. For example, a GP working in an urban area of south east England described her practice:

It's a very mixed inner city practice. We're an area of high deprivation. It's a very mobile population, so we do see a lot of people for a short time. There's a fair number of homeless people, there's a lot of mental health problems. Also there's a large contingent of people that will be in professional roles, and it's the whole spectrum really. A huge amount of different cultural backgrounds, of course, as well. [SE GP_5]

A personal sense of community belonging appeared to be related to a sense of caution in being involved in physician assisted suicide because of how they might come to be identified within that community.

The doctors working in more urban settings appeared to believe that they had a good knowledge of their patients' community but none described a sense of belonging to those communities and referred to them in language suggesting 'otherness',

So yes, I get to know patients, where they live, how they live, go and visit them in their homes, not as much as we used to. We walk the streets that they live on, we know the shops that they use, we know the pubs that they drink in. You get a feel for a community, and the people who live in the community. [SE GP_6]

The rural doctors however identified themselves as an integral part of their local communities which presented particular challenges in relation to being involved in assessment of patients requesting physician assisted suicide. One doctor in particular identified a potential conflict between her role as a rural palliative care consultant and involvement in physician assisted suicide,

The other problem I could see for me personally...We live in the same communities we serve with a rural service, everybody knows us. I suppose I'm already Dr Death. If I'm calling at somebody's house it means there's something going on, but if I was also associated with the physician assisted suicide part it would be incredibly complex to get the message out to the bulk of the population that I'm here to serve that seeing me doesn't mean I'm going to be part of arranging for an physician assisted suicide for them and/or overdosing them with the... I spend most of my professional life persuading people to take strong opioids and they're not going to harm them in any way. So that would be extraordinarily difficult to manage the message. [NE Doc_2]

4.2.3.1.2.2 Social and cultural community

Beyond the immediate geographical community among their patients, several doctors considered their involvement in assessment of patients requesting physician assisted suicide from the perspective of their position in their own social environment. This was again generally viewed negatively and carried with it a sense of being publically identified as a doctor who was willing to participate in the process.

One doctor, who identified themselves as opposing physician assisted suicide, was particularly concerned about this and expressed concern that he might be socially ostracised,

I don't want to be involved in it to be honest but it's not a particularly religiously objection but I don't particularly believe in it for lots of reasons. But if I was personally involved I know that if it was found, became public knowledge, there would be people socially who wouldn't want to speak to me again. It's going to be that level. [Wales Doc_1]

The same doctor also voiced concern about the potential ramifications of being publicly identified, and potentially vilified,

I'm not a pop star. So I think no, to be in the media spotlight, to have people making judgments that would be a real concern. And what you hear about the US and when it comes to abortion is a bit scary. We're living in a different era now and you can be got at very easily at by pressure groups and I think a lot of people would be very scared actually to be involved for that reason, particularly if there were pro-life people who got on the bandwagon. [Wales Doc_1]

This concern appeared to be stronger for those whose personal ethical position did not align with legalisation of physician assisted suicide. One doctor who identified himself as strongly in favour of physician assisted suicide anticipated the potential for negative publicity but did not see this as particularly aversive,

So I would like to think I wouldn't care if the *Daily Mail* wrote about me, and certainly it would not stop me being involved in end of life decision making. [SE GP_3]

4.2.3.1.2.3 Professional community

Two concerns emerged when considering the wider professional community, firstly, the implication of involvement in physician assisted suicide for the profession as a whole and secondly, what involvement in physician assisted suicide would mean for the individual as part of that community.

The main concern expressed, especially by those who opposed legalisation of physician assisted suicide, was that the practice of physician assisted suicide would run counter to how the medical profession views itself,

Yes, it's a bit frightening actually, the whole idea, because obviously none of us have had that... I'm not going to get into the ideology of it for a minute but just the practicalities of it, none of us have been trained to believe in that, if you see what I

mean, none of us have been trained to think in that way. We don't take an oath but the Hippocratic Oath, if it exists, in theory says, 'Do no harm...' and all the rest of it. So I think it would be quite a massive culture change for people to be thinking like that, to be honest, and it would change the flavour quite a bit of discussions. [Wales Doc_1]

Those in favour of physician assisted suicide however saw involvement in physician assisted suicide as an opportunity for much needed development and change in the medical profession,

...for me it would be important to look at this, because medicine has changed. For me the counter argument of saying, 'We went into medicine to prolong life.' We don't talk about prolonging life really; we talk about quality of life. Because we can prolong life now much longer than we ever could, but you have to balance that with quality. So for me, because medical practice has changed, this makes this a much more valid option than it would have done maybe thirty or forty years ago, when people often wouldn't have got to this stage because they would have died much quicker. So I think that as we improved our medical practice we have to think about the negative impact on that and try and minimise that with other options. [SE GP_4]

From a personal perspective, some of the doctors were concerned about being labelled by their professional peers if they participated in assessments, fearing the implications of being 'the doctors that do' and how that position would be viewed by the medical community, with the potential to be divisive,

I would be a little worried that that would again create this two tier type of doctor. The doctors that do, and the doctors that don't. How that would define you, and what that would mean about you, all sorts of things. And us as a medical profession, would that divide us? [SE GP_4]

4.2.3.1.2.4 The clinical team

Several of the doctors, particularly those in hospital practice, but also those in collective GP practice, talked of the potential conflict that participation in assessment of patients requesting physician assisted suicide might cause for their teams, especially where there might be differing views on whether physician assisted suicide should be an option for terminally ill patients,

I suppose you could have examples where you might have, I don't know, would you have a consultant or a palliative care team leading the team that was against? Nurses who were actually going out and seeing patients who were pro? How would that work? Would their agendas be different? How would you negotiate that? [SE GP_4]

One doctor (an oncologist) expressed his concern about the potential effect on the clinical team in reference to the experience of clinical teams in countries where physician assisted suicide is legal,

We haven't, thankfully, had the opportunity or had the requirement to explore these things in the way it really happens but we know from other places that it causes a lot of discord in teams when this happens. [Wales Doc_2]

4.2.4 Conceptualisation of mental capacity

The findings showed that conceptualisations of capacity varied across the sample ranging from a 'cognitive' conceptualisation to a broader conceptualisation encompassing a range of elements including motivation, values and voluntariness of the decision.

At one end of the spectrum the decision to request physician assisted suicide was conceptualised as an intellectual one and the capacity assessment process should be conducted in order to determine that the applicant has sufficient intellectual/cognitive ability to make the decision. For example one General Practitioner (who stated that he was in favour of physician assisted suicide) talked about identifying cognitive impairment as the main task involved in the process.

...obviously look into their background, see what possible impairments there might be. You know, why is this patient's capacity in question? And I'd probably do a couple of simple mental state tests...[SE GP_3]

This doctor considered the process to be quite straightforward for the majority of patients and no different from capacity assessment in other healthcare contexts. He took a 'professional' perspective in his approach to mental capacity assessment for assisted suicide.

Doctors who saw capacity determination mainly as an assessment of cognitive ability to make the decision talked more about using the Mental Capacity Act and assessing according to the four step test set out in the Act,

I mean, first of all, you define your decision, then you decide whether somebody had a disorder of mind or brain, which means they might lack mental capacity, and then you assess whether they can understand what their options are, whether they can – I can't remember the second one – remember what their options are, or something,

whether they can make an informed judgement, and whether they can communicate that decision, and that's it. [SE Psych_1]

At the other end of the spectrum doctors conceptualised capacity more broadly than having the cognitive ability to make the decision. These doctors were keen to look at whether they thought the patient might be being manipulated by others as part of the assessment and would want to look the decision as part of a wider context of their enduring values and beliefs,

...you get to know people's life plans, for want of a better term, and what their vision of themselves in the world is...And so, you can see that, 'Yes, this makes sense within the context.' [SE GP_6]

These doctors also talked about wanting to explore the reasons why patients had made this decision in order to help them decide whether the decision was capacitous e.g.

I think I would think of it just in a broader term than I would if you're thinking about an operation or something like that, because I think perhaps I'd start somewhere different. Perhaps you would have to start examining their fears about dying...Because I think so much fear surrounds dying, and it's very understandable that people don't want to die in a hospital, in a very impersonal environment, with tubes all over them, or be on a machine that somebody has to switch off, or all of these things. And so in assessing somebody's capacity you'd want to discover why they want to end their own life....I would also want to examine their feelings for their family, because I would fear that many people would want to end their lives early purely not to be a burden on others....[SE GP_5]

There did appear to be a tendency for the psychiatrists to adopt a more 'cognitive' conceptualisation of capacity and base their conceptualisation upon the Mental Capacity Act test of capacity, including wanting to assess whether mental disorder such as depression might be impacting upon the applicant's ability to weigh the decision in the balance. There were exceptions to this approach though, especially WalesPsych_4 whose conceptualisation was more broad/holistic. This doctor expressed views in strong opposition of the legalisation of assisted suicide based on his belief in the sanctity of life. Whilst he stated that he believed in rational suicide he did not believe in rational *assisted* suicide. He considered the Mental Capacity Act 2005 inadequate as a framework for assessment of capacity and stated that he would not presume capacity if he were making an assessment and would want the patient to prove their capacity to him. He expressed his concern about the imposition of the doctors'

views and values on the capacity determination process and given his acknowledgement of his own values considered himself to be unsuitable for the task.

...it's the sort of decision for which you have to be absolutely sure that you have absolute capacity, and the way that capacity is defined with the judgment element about balancing and the stuff that we were talking about earlier, I think that's almost impossible to get to. The more I think about it the more I... it's not a dreadful idea but I think in practice it would be an absolute nightmare [Wales Psych_4]

4.2.5 Models of mental capacity assessment

This section explores how the doctors conceptualised mental capacity assessment both in their current clinical work and for assessment of patients requesting physician assisted suicide.

4.2.5.1 General models of mental capacity assessment

Within the sample, two models of capacity assessment were described. Firstly, 'formal' capacity assessment, usually requested by another professional or organisation e.g. an assessment of testamentary capacity, in which the focus of the patient encounter is to determine capacity, where the assessment process is documented and the outcome is returned to the person requesting the assessment. Secondly, 'informal' capacity assessments, perceived to be part of their ordinary clinical encounters with patients and taking place during most of these encounters. These assessments were not normally documented or structured. In many cases these were not seen prospectively as an assessment of capacity but as an implicit part of the clinical encounter.

Those doctors who did not describe these 'informal' capacity assessments thought that they rarely engaged in capacity determination,

I don't think I've ever done it....Possibly, I may have been asked an opinion in writing about a patient or two, but memory escapes me. So it's not something I'm involved in, essentially. So my knowledge of the procedure is theoretical rather than practical. [SE GP_3]

whilst those who did thought that they assessed capacity very frequently,

Well, there's an interesting distinction between a very formal and an informal capacity decision, because obviously one needs to be making mental capacity assessments all the time, with regard to the range of treatments, but probably very formal or difficult mental capacity decisions; probably once every couple of months, but obviously every day to some extent. [SE Psych_2]

The psychiatrists in the sample tended to think of capacity assessment as more integral to their daily practice than the other professional groups, with the surgeons in particular seeing capacity assessment as something that would need to be done rarely. The general practitioners and palliative care physicians varied in their views about how integral capacity determination was to their daily practice.

A formal mental capacity assessment was not exclusively triggered by an outside request but perhaps by something about the patient's decision that caused concern or raised a question about capacity. In these cases the doctors themselves moved from an 'informal' to a 'formal' model.

Well, it's in the back of your mind virtually all the time really, and I think you'd move on to formalise it when it's a more significant issue, or you suspect that other people might have different views, or there might be problems with relatives, that sort of thing. [Wales Psych_5]

Several of the doctors were candid in their opinion that they tended not to question capacity when the patient made a decision that met with the agreement of the treating team or 'seemed' appropriate, but would question capacity if a more unusual or 'unwise' decision was made,

We only ever really question someone's capacity if we think that what they're going to do is a bit wrong. If we think that what they're going to do is okay, then we tend not to get too worried and too exercised about the capacity, being perfectly honest! [SE GP_5]

So whilst patients are in hospital and they agree with having chemotherapy or radiotherapy, then we think, 'Oh, that's fine.' If you have a patient that suddenly says, 'I want to stop treatment,' halfway through, so somebody may have a primary brain tumour and they've started their treatment. The treatment is to have 30 fractions or 30 doses of radiotherapy, and after 6 they want to stop, then people would say, 'Hang on, that can't be the right decision and somebody needs to go and speak to them.' If they then restart treatment, we think, 'Oh, that's fine.' If they continue to stop, we think, 'Oh, have they got capacity for that decision?' [Wales Doc_3]

Despite these views, there was a goal expressed in the majority of interviews that capacity determination should be as 'objective' as possible or that this was the ideal to which they should aspire.

4.2.5.2 Models of mental capacity for physician assisted suicide

All of the doctors considered a capacity assessment for patients requesting physician assisted suicide to be 'formal' and should therefore be done explicitly, with the process and outcome documented.

4.2.5.2.1 Presumption of capacity and the appropriateness of the Mental Capacity Act

2005

There was a fairly even split between those doctors who would and would not presume capacity for patients requesting physician assisted suicide with a third presuming capacity, a third explicitly not presuming capacity with the remainder either having not discussed it or being unclear on whether capacity would be presumed.

Of the eight doctors who stated that they would presume capacity, five stated explicitly that they would assess capacity using the principles of the Mental Capacity Act. Of the eight doctors who stated that they would not presume capacity, three stated explicitly that they would assess capacity using the principles of the Mental Capacity Act. Only one of the doctors who stated that they would not presume capacity stated that the Mental Capacity Act was not suitable for assessment of capacity in patients requesting physician assisted suicide (see Table 7)

Table 7: Conceptualisations of mental capacity among senior doctors in interview sample

		Presumption of capacity				Total
		Yes (%)	No (%)	Unclear/ both (%)	Not discussed (%)	
Mental Capacity Act	yes	5 (45)	3 (27)	2 (18)	1 (9)	11
	no	0 (0)	1 (100)	0 (0)	0 (0)	1
	unclear	2 (50)	1 (25)	0 (0)	1 (25)	4
	Not discussed	1 (13)	3 (37)	0 (0)	4 (50)	8
	Total	8 (33)	8 (33)	2 (8)	6 (25)	24

On examining views about presumption of capacity by professional group, the psychiatrists stated that they would presume capacity more frequently than the hospital doctors or GPs.

The GPs stated more frequently than the other two groups that they would not presume capacity with half saying that they would not presume capacity for this decision (see Table 8)

Table 8: Presumption of capacity for terminally ill people requesting physician assisted suicide among senior doctors in interview sample by professional group

		Presumption of capacity			
		Yes (%)	No (%)	Unclear/Not discussed (%)	Total
Professional group	Psychiatrists	5 (56)	2 (22)	2 (22)	9
	Hospital Doctors	1 (14)	2 (29)	4 (57)	7
	General practitioners	2 (25)	4 (50)	2 (25)	8
	Total	8 (33)	8 (33)	8 (33)	24

On examining views about the appropriateness of using the Mental Capacity Act by professional group, two thirds of the psychiatrists stated that they would use the framework of the Mental Capacity Act compared with around a third of the hospital doctors and GPs. None of the hospital doctors or GPs stated that they thought the Mental Capacity Act would be inappropriate (although the majority were unclear about whether or how they would use the Act) compared to one of the psychiatrists. Only two of the psychiatrists were unclear on or did not discuss the use of the Mental Capacity Act compared with around two thirds of the GPs and hospital doctors. (see Table 9).

Table 9: Support for the use of the Mental Capacity Act for people requesting physician assisted suicide among senior doctors in interview sample by professional group

		Support for use of Mental Capacity Act 2005			
		Yes(%)	No(%)	Unclear/ Not discussed (%)	Total
Professional group	Psychiatrists	6 (67)	1(11)	2 (22)	9
	Hospital Doctors	2 (29)	0 (0)	5 (71)	7
	General practitioners	3 (38)	0 (0)	5 (63)	8
	Total	11(46)	1 (4)	12 (50)	24

The psychiatrists discussed the use of the Mental Capacity Act as a potential or actual assessment framework more frequently than the other doctors during their interviews (7/9 vs 2/5 of the hospital doctors and 3/8 of the GPs).

There was a difference between psychiatrists and the other doctors in whether they said they would presume capacity for patients requesting physician assisted suicide. Just over half of the

psychiatrists said that they would, compared with a quarter of the GPs and only one of the hospital doctors (a surgeon). None of the doctors working in palliative medicine or oncology said that they would presume capacity for this decision.

Five of the 24 doctors stated that they would both presume capacity and use the Mental Capacity Act to assess capacity, four of whom were psychiatrists and one of whom was a GP; two of these (a GP and a psychiatrist) stated that they were strongly in favour of a change in the law to allow physician assisted suicide, one (a psychiatrist) stated a position against a change in the law and two did not state a clear position.

4.2.5.3 The relationship between views on legalisation of assisted suicide and approach to assessment of capacity.

The doctors who did not support legalisation and viewed requests for physician assisted suicide as an expression of distress or the manifestation of unmet need or mental disorder appeared to see the assessment as an opportunity to identify reversible factors, ameliorate suffering and ultimately seek to dissuade the patient from continuing with physician assisted suicide,

So I guess I would be coming at it a trying to put them off probably. It would be like an advocacy thing in a court, I'm trying to test them out by disproving it to them, as it were, and I'd want to explore any other considerations. [Wales Doc_1]

The doctors who were in favour of legalisation, and more accepting of a request for physician assisted suicide as potentially rational, did not talk about dissuasion or searching for meaning.

They looked upon capacity assessment as more of a checking process,

...of those who are sympathetic to this sort of thing happening, it may well be that most of them, a large number, are happy to rubber stamp a decision where there's no question about capacity.[SE GP_3]

Because it's a grave decision, then the capacity one must have to take that decision is pretty serious. However, my mindset would be, 'You probably have capacity, let me just check that you do.' [SE GP_6]

Attitudes to physician assisted suicide appeared to influence whether the doctors would presume capacity for the decision. Two doctors for example, who identified themselves as strongly in favour of physician assisted suicide, were clear about their presumption of capacity,

I imagine that my default position would be, unless I can really, really prove why they can't, they should [Wales Psych_3]

INT Do you think it's appropriate to presume capacity if somebody is requesting assisted dying?

RES I think it's offensive not to. [SE GP_6]

In contrast, a psychiatrist who identified himself as opposing physician assisted suicide stated clearly that he would presume a lack of capacity for physician assisted suicide, expecting the patient to demonstrate that they had capacity for the decision,

I don't know, again it depends what the decision is. If someone is running across the M4 would you presume they've got capacity to do that or would you presume they haven't? You presume they haven't and you stop them. So this, you might presume they can decide whether they have sugar in their tea but you wouldn't presume they can go and kill themselves or get killed until they've... in my mind, I don't think we would presume that they had capacity to do it and actually no, I would see it very much the onus is on them to prove to me that they had capacity. [Wales Psych_4]

An exception to this distinction however, was one GP who identified herself as in favour of physician assisted suicide took the view that capacity should not be presumed on the basis of the gravity of the decision being made,

INT Again, do you think that it's possible to assume capacity when somebody makes a request like that?

RES I think that's probably the reverse in that situation. I think you have to specifically go out of your way to find evidence to prove their capacity, to document that you had. I think most of us would try and do that when the patients were making big life changing decisions. So, patients deciding to stop treatments, you would look for evidence to prove that they had made an informed decision and that they did have the capacity to make that decision.

INT So the burden of proof is the opposite for decisions that have bigger implications?

RES Yes [SE GP_4]

4.3 Section 2: The process of getting to know in order to arrive at a sense of knowing

4.3.1 Getting to know

Many of the doctors described 'getting to know' their patients, a process essential to gaining a sense of 'knowing' which was important for assessment of capacity. This process comprised three interacting key elements: 1) Temporality (the importance of time in gaining a sense of knowing), 2) Dimensionality (developing a sense of knowing through experiencing the patient in a number of different dimensions both personally and through others) and 3) Quality (being able to interact with the patient in a meaningful way in order to generate a sense of knowing that is personally satisfying).

4.3.1.1 Temporality

Time was described both within individual consultations and across the span of contact with a patient as an important factor in the process of getting to know.

The hospital based psychiatrists and palliative care consultants in particular highlighted time spent with patients during individual encounters as a key to their ability carry out a 'good' assessment. They described how with more time they were able to do a 'better' assessment of the patient that went beyond 'face value' and that this potentially impacted on outcomes:

So I spent some time talking to her and she was somebody who was very lonely. She kept all of her feelings very much bottled up and she was somebody that was kind of, in that covert way, actually asking for help and she wanted to see that somebody would take time to just talk to her. Once I had done the psychiatric assessment and explored all of that with her, she was actually quite keen to have treatment. [Wales Psych_2]

In contrast, the general practitioners and the community psychiatrists described multiple shorter encounters often over many years as the foundation of their relationships with patients

Usually it's because I've either known someone for a long period, yes it's usually quite a long period. I've been in the same job, on the same patch, for fifteen years. So there's quite a few people that I've seen repeatedly over that time period. [Wales Psych_5]

In thinking specifically about mental capacity assessment, temporal exposure was felt to provide a sense of context to the current decision being made in terms of its continuity or discontinuity with the patient's previous presentations, stated wishes and process of decision making in the past.

One GP reflected on her temporal relationship with her patients not just in terms of how long she had known them but also for how long they had known her during her many years practicing in one surgery, and how the sense of knowing was for many patients reciprocal:

Unfortunately, like I'm getting older they're getting older. Thirty years ago they were in their fifties and now they're in their eighties. So you look at people and go, 'Tch,' but they're the same people that when you start you're seeing, and they're now elderly. So they're liking me because I was the young doctor then, and I'm probably still the young doctor. [Wales GP_2]

In contrast however, one hospital doctor compared his contact with patients with the more sustained contact of his nursing colleagues and felt that this sustained contact might provide a better foundation for a good assessment of mental capacity,

...the specialist nurses sometimes will have more contact with patients and may actually be in a better position to make a judgement than a doctor who sees a patient for relatively brief consultations distributed over a period of time. [NE Doc_1]

And similarly one GP was critical of the model of multiple brief encounters with patients in the consulting room, feeling that there was a risk of missing important contextual information,

I mean sometimes as a GP even though we are supposed to be close to the patient we may not know them particularly well. You only see them in the consulting room and you really have no idea what's going on at home and it's clear very often, again with the elderly that they can come across as having mental capacity and knowing exactly what they're talking about but actually if you spent a day with them you'd realise that they didn't really have a clue as to what's going on. I think that people are very good at hiding that. [Wales GP_1]

In addition to specialty specific constructs governing time spent with patients, the nature of the medical condition presented was also felt to impact on temporal relationships and sense of knowing. In thinking more specifically about mental capacity determination, brief single encounters were considered to be potentially risky because a sense of knowing might not be established before a decision needed to be made e.g. somebody presenting with an overdose

refusing appropriate emergency treatment. This was contrasted at the other end of the temporal spectrum with patients with long term conditions such as progressive neurological conditions, where the doctor might have developed a relationship with them over an extended period of time:

As I said before, perhaps less so nowadays, but people with chronic conditions, they are likely to know their patients. Huntington's disease is a good example, motor neurone disease. Progressive neurological disorders, people tend to be under care for years or often for years before they get to their point where they've decided that they want to go for assisted dying, for example. Therefore I think that longitudinal knowledge of somebody is going to be very helpful in terms of assessing their capacity. [Wales Psych_6]

In the main, the GPs felt that the longitudinal relationship was important for a good assessment of capacity. One GP in particular felt this to be so important as to be a prerequisite for involvement in the process,

And I think if I was asked, 'Does that patient have capacity? Have you known the patient for a significant length of time? Does this request appear to you, having known the patient well over a significant period of time, to be congruent with your knowledge of the patient?' And to be asked to make a declaration on that, a professional declaration on that. I would feel that that would strengthen the legislation. So you're not just asking is the patient competent, you're asking me, 'Based on your knowledge of this patient over two years, is this congruent?' And I can say, 'Actually, yes it is,' or, 'Do you know something? It's not.' [SE GP_6]

In contrast to the GPs, the oncologists and palliative care consultants especially felt that whilst a longitudinal relationship was very valuable, it was possible to get to know a patient over a shorter period of time at a higher intensity of contact,

Okay, well I think oncologists know their patients in... there is a lot of variation from patient to patient. There are some patients who we know, because we've looked after them for several years, and even if you looked after them for six months, there can be a very intense relationship because you're talking with them about such important things and they come to depend on you as their doctor in a very particular way. So that can be a very strong sense of knowing and that provides a context for the really personal and very real conversations that we've been talking about....you can get to know people very quickly when you're dealing with them in a very intense situation in a short-ish time. [Wales Doc_2]

This contracted process of getting to know appeared to be facilitated by a level of physical or emotional jeopardy experienced by the patient and acknowledged by the doctor and, or a short life expectancy forcing expediency in the interaction. This appeared to motivate both

doctor and patient to engage in an intense process of getting to know in order to be able to address the problems being presented.

4.3.1.2 Dimensionality: 'Building the bigger picture'

One of the key tasks the doctors identified in being able to determine capacity for physician assisted suicide was to be able to put the request in to a wider framework or 'bigger picture' and that knowing the patient was a way of being able to achieve this.

The development of a sense of knowing the patient was derived from both direct and indirect interaction with the patient's history and current situation.

The doctors described getting to know the patient directly through consultation with them, but also talked about other sources of information that might allow them to build up a sense of knowing to provide a number of perspectives and opinions on the situation, which would then give them a richer basis on which to base their decision making. Key sources of this indirect information were the patient's family and other loved ones, the clinical record, and discussion with medical and other professionals working with the patient.

So it would be talking with him myself, quite frequently over a fairly long period of time. Also his GP and social worker, and support worker spoke with him about his understanding of the health issues. And talking with family members as well. {SE Psych_2]

Family members were felt to be a particularly rich source of information about the patient, and several doctors said that they would want to speak with the family directly. It was also felt to be important to ascertain information about the patient's family in order to determine whether there were any family relationship related factors impacting on the decision to request physician assisted suicide,

Well, there might be a lot going on with the patient, there might be a lot going on with the patient's wider network, family, social support... [Wales Psych_4]

This was thought to be especially important in terms of identifying if the patient was being placed under pressure or coerced to hasten their death perhaps for financial gain,

But I mean there's a number of routine enquiries one would make about, when a patient came with this, and that would include asking about all of their family and what they think about it. And have they talked to them, and what their

circumstances are in terms of their social circumstances, their financial arrangements, you know, all of that sort of thing. It doesn't take very much, for alarm bells to start ringing, when anything of those comes up positive. And that's again about appropriate antennae, I suppose, to people's situations [SE GP_3]

A lack of family or close social contacts was identified as a potential barrier to getting to know the patient. This was especially identified by the doctors working within the urban communities,

I think the most difficult situation is where a patient like this has no apparent relatives or friends to fall back on, so that you can have a reasonable discussion with them and their relatives [SE Doc_1]

Within the consultation, an understanding of the patient's cultural background, their personal values, their community and their social circumstances were key areas of enquiry. Knowledge of these factors both from the patient and through other information sources could then place the patient's current decisions in their personal, social and cultural context in order to assess their consistency with that context. One doctor described their assessment of a man with advanced disease who expressed a wish to end his life,

He was a typical Welsh working-class man who when you went through what his wants were, so what would give him pleasure in his day, so the problem was he had no pleasure in his days. [Wales Doc_3]

Gaining a sense of patients at other times in their lives was also felt to be important in contextualising the present,

I think that in terms of knowing that you had the background knowledge of the patient at maybe a different time in their lives, would be enormously helpful in interpreting what they were saying about wanting to die now, in this example. [SE GP_2]

Also, having a sense of how they were making other decisions within the current situation was felt to be helpful,

And also I have had an opportunity to start forming an assessment of capacity. Because it's unlikely that assisted dying is the only significant decision that we will take through the course of supporting somebody through the dying process. And there will be, 'Do you want to go to a hospice? Do you want to have surgery? Do you want to have chemo? Do you want to have radio? Who do you want us to help

you tell? What supports do you want in the house? What is it you're trying to achieve? Do you just want to sit there comfortably and fade away, or have you got things that you need to do?' And in the course of those conversations I would imagine I would have a pretty good idea of the person's capacity. [SE GP_6]

Within the direct patient interaction, a range of sensory information might be used in the process of getting to know, for example one doctor described how he would often utilise visual cues in order to gather information about what was important to the patient and then use these as facilitators to further discussion,

You can try and pick up things about family photographs... I think what we've got to remember is that patients only have so much space. They only have a top of a locker to put their most precious or valued items, and I think if we all had to hone down into the top of a locker for pictures, then we would probably put ones that have importance to us, so I often start with whatever picture might be there, or drawing, that a patient has often struggled to keep upright because people knock it over, people come and clean around it, they put it down flat, so if it's upright I'll say, 'Who's this?' and try and find out if family or friends or pets are important to people and then to try and get a value or some sort of sense of what sort of values they have as a person. [Wales Doc_3]

4.3.1.3 Quality: 'Hitting it off'

A less easily definable but equally important factor in the process of gaining a sense of knowing the patient was a perception of quality in the doctor patient interaction(s), referred to as 'hitting it off'. A high quality interaction with the patient was thought to facilitate the development of a sense of knowing whilst a persistent sense of low quality in the interaction might mean that a sense of knowing could never be reached despite a large volume of information about the patient, and multiple contacts with the patient over a long period of time.

The difficulty is you can't always get there. I would say that there are, in the years that I've been practising, there are a few patients that I'm not really sure I've ever got there. [Wales Doc_3]

This perception of quality appeared to be a perception of interacting with the patient 'person to person' rather than 'doctor to patient' and gave a sense of authenticity in the developing relationship,

Well, I think it would depend on how much contact the doctor had had with the patient in question, how in depth that contact was, whether they'd had a fairly technical role with them or whether they'd had more opportunity to speak with them person to person. [NE Doc_1]

Reasons for ability to 'hit it off' with some patients and not others included a sense of shared values, a perception of cultural 'fit' or in some cases a sense of liking the patient.

...you can empathise with an Irish or a Scotsman and kind of understand what they're on about, really. And they're the men of the world, really. [SE Doc_1]

Although this sense of 'fit' was seen as a potential driver for a good quality relationship, it was also felt possible to develop a sense of knowing without agreeing with the patient's perspective or supporting their decisions on a personal level, by being able to establish an authentic understanding of their 'value base' based on a resonance with their professional and personal experiences with similar others or situations. A sense of interpersonal congruence was described based on a resonance of values, personality factors and empathy.

The conditions in which 'hitting it off' could develop required a level of ability and commitment from both the doctor and patient. From the doctor, a willingness to engage on a personal level, being 'open', committing to discovering the patient's narrative and 'finding the agenda' were all identified as important,

Well, by having long discussions with him and asking him to explain back to me in detail why he had made his decision and what the pros and cons of that were, and really making a judgment based upon his narrative, if you like, as to whether I felt that he did have that ability. [Wales Psych_6]

The theory of good, it's all down to the theory of good consultation. The more narrative you allow, the more you know about the patient. [SE GP_1]

One doctor described her experience of how some doctors are better at committing to finding the agenda and meaning in the presentation than others, which is a reflection of the quality of the doctor and might impact on the outcome of the assessment,

Some doctors will be more attuned to it and more thoughtful of it. Some doctors will just take things much more on face value. 'You said you had a cough, I've examined you, this, that, the other. Go away.' Other doctors will say, 'Why is this person coming with a cough when I know they've got a PhD, they've Googled it, they don't need to come in and tell me they've got a cough. What's happening?' There's

a quality issue about the doctors that you're seeing, which is not just a problem for this, it's a problem for everything. [SE GP_4]

In order to establish a good quality relationship, the active role of the patient was identified, with them needing to be willing to 'be known', and commit to the process of 'getting to know'.

Yeah, yeah, and perhaps that's partly dependent on the patient as well. Some of them open up more, share more of their lives with you really. [Wales Psych_5]

The non-participation, or inauthentic participation of the patient was identified as a key potential barrier to getting to know. The immediate condition of the patient might be responsible for this, e.g. experiencing distressing physical symptoms,

I think some patients need longer to establish a rapport with than others, and that's perhaps because there are other issues – so maybe pain, nausea – that need tackling. [Wales Doc_3]

but other factors might be relevant in the specific circumstance of having to present to the doctor for an assessment of capacity for physician assisted suicide. One psychiatrist described what they felt the consultation might be like for the patient and how this might present a barrier to being known and jeopardise the quality of the encounter,

I would imagine that they would feel they would have to be on their absolute best behaviour because they think, 'Oh, they think I'm mad, that's why they've referred me to the psychiatrist. I've got to prove to them that I'm not.' Therefore you would wonder about how truthful they maybe in some of the things if you're asking them about their history of mental illness or things like that, and I think to a certain extent people know what you're asking them and people change what they tell you because they know what the correct answer is and what the not correct answer is. So I think if everyone ends up seeing a psychiatrist and it's just the standard then it maybe that they start from a position of this is routine, I'm just going to go in and say my piece and this is what happens to everyone. If they've already been assessed at that point they may feel very upset or rejected or desperate, 'No, one's listening to me, no one's paying... they think I'm mad, they don't think I mean this.' So that encounter then could be quite fraught. I would wonder if people would minimise if they did have any mental health symptoms, not to want to think, 'Oh god, if I say I've ever been depressed they won't let me do it because they'll think it's all in my head.' So you may wonder for some people if the quality of the information you're getting is entirely correct or if they would... I don't know, just downright lie maybe. I don't know, I can't imagine... possibly quite angry that they're having to come and see us and maybe quite rejected as well. [Wales Psych_3]

Lastly, pragmatic barriers were identified which included patients' cognitive and sensory impairment, lack of a common language, and the pressures of a busy service limiting the doctor's ability to engage as meaningfully with the patient as they would wish to.

4.3.2 Sense of knowing

Whilst a sense of knowing the patient was identified as key to the process of capacity assessment for most of the doctors, its definition was elusive within earlier interviews. When asked specifically what it was to 'know' a patient in later interviews, definitions were offered that alluded to rich and nuanced understanding of the patient with some sense of reciprocity,

There's a kind of a density to the fabric of the relationship. [SE GP_6]

I suppose it's a bit like a jigsaw...you can have an impression of what they're like when they're at their best, what they're like when they're at their worst, and you build up information from family and other areas, perhaps support workers, police, all building up a picture. It's difficult to define but there's just some patients that I feel that I know well, and others that perhaps I've seen for a similar length of time but I don't really know what they think and believe about things. [Wales Psych_5]

There were differences in the way the professional groups described their sense of knowing and these descriptions seemed to reflect their specific professional backgrounds and culture.

The General Practitioners for example often talked about knowing their patients in the context of populations, communities and families,

But for many people you just get to know them and it's more of a chat with somebody that you know. And you know what they do, you know where they live, you know where their children are studying at university or things, because that's one of the joys of general practice really. And although we're losing that, as the practices get bigger and bigger, and obviously we've lost it to a certain extent, it still happens. So, and it's what we would like to hang onto, because it is very valuable. [SE GP_5]

The psychiatrists and other specialist doctors however, talked more about their patients as individuals and in the context of the condition or problem with which they were presenting.

4.3.3 Risks in knowing the patient: a threat to valued objectivity

Whilst knowing the patient was generally thought to be an important basis for capacity determination, a number of doctors expressed concern about potential pitfalls that could be

encountered when the patient is known, especially if there was a sense of a 'bond' having formed between them and the patient.

Some saw knowing the patient as a potential source of bias in the process whereby the established doctor patient relationship could threaten their sense of objectivity in the assessment-an objectivity that was thought to be important to maintain in order to perform a 'good' assessment of capacity,

...developing an emotional bond with a patient as well could impact on one's objectivity. I think it's one of those complex situations where I definitely would not say that you should definitely not be allowed to assess somebody's capacity if you've got any knowledge of them before and likewise the other way round. I just think that you need to take those into account when performing your capacity assessment. [Wales Psych_6]

I suppose you've got more invested in it, you're probably less detached and objective. [Wales Psych_5]

The relationship formed with the patient was seen as a potential area of weakness that might lead to decisions that might be inappropriately collusive and potentially wrong,

...it's difficult to know when you're being manipulated and when you're not, when you've had a long relationship with people. [SE GP_4]

I think the longer you know somebody, the greater the collusion is with their situation as a doctor [SE Doc_1]

4.4 Section 3: The spectrum of knowing

The findings showed that within the doctor patient relationship there was an individually conceptualised, but difficult to define optimal sense of knowing, beyond which it was felt possible to know the patient *too well*, a state which might result in the loss of the professional objectivity needed to do a 'good' assessment of mental capacity.

When talking about their a priori models of capacity assessment for physician assisted suicide, the legal framework of the Mental Capacity Act was discussed by almost half of the doctors.

However, when talking about how in clinical practice the doctors would go about assessing capacity, a pattern emerged whereby having a sense of knowing the patient might lead the doctor to rely less on the formal assessment procedure of the Mental Capacity Act and use a

less structured, more pragmatic 'gut feeling' approach based on their knowledge of and relationship with the patient,

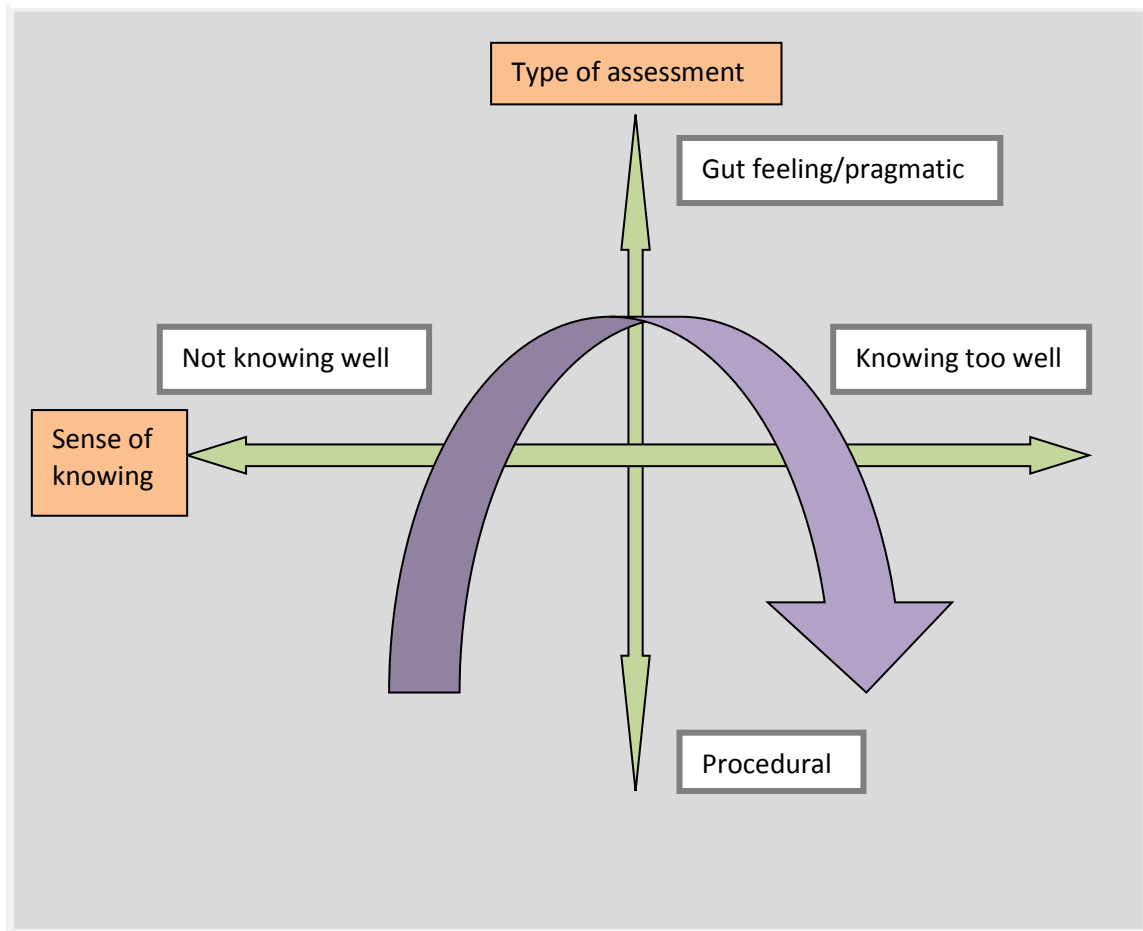
Well, no, but the tick box exercise is easier then [when the patient is known] because, you know, a question on a tick box, 'Does this person have mental capacity?' is a very easy tick box and you can just say yes or no...So it may not be as structured... what will I say, if you have a three page document that you have to get through you will make sure that somewhere in there you have answered the questions. And if you haven't, you will sit down with the patient and say, 'Look, I just have to go back over a couple of things because I'm not sure if I've done them. We've sat here and we've discussed this for the last hour and I understand and I know exactly where you're coming from and I know what you want. I know that you would like to die in the company of your family and they are all very supportive of that and I know you have capacity to do it, however, I just need to go back and look at the tick boxes and make sure we've ticked everything so as to make sure we're legal.' [Wales GP_2]

This pragmatic approach reverted to a structured approach however once there was a sense that the patient was known 'too well', or that the doctor became aware that they were making a personal value judgement about the patient's decision. This was proposed in an attempt to bring some objectivity back into the process in order to protect both the doctor and the patient from the potential for making an inappropriate decision either for or against proceeding with physician assisted suicide,

It's invariable in life that if you know this particular patient, or this particular person and you know the history, you do have assumptions. Whether you have to challenge your assumptions, that's another question. ..First of all, we all have assumptions and our assumptions may or may not be right. Unless you go through the whole thorough assessment and procedure, you may be carried away with your bias, prejudice, wrong impressions and assumptions. Whereas if you go through the algorithm of full assessment, that is the way to challenge your assumptions...It's just to give the patient the fairness. And [protecting the patient from] my own agenda, exactly....To make it more objective, rather than subjective between I and the patient. [SE GP_1]

A model of the relationship between the sense of knowing and the approach to determination of mental capacity assessment is illustrated in Figure 4.

Figure 4: Model of the relationship between the sense of knowing and the mode of decision making in the assessment of mental capacity for assisted suicide.



4.5 Further exploration of the emerging theory through discriminant sampling: the experience of assessing patients for liver transplantation.

Once the model of the relationship between knowing the patient and approach to assessment emerged, I sought to test whether the model held in another clinical situation.

In order to do this I interviewed two practitioners working in a liver transplant service, a social worker and a nurse. Both had been in their current role for a number of years and were in senior positions. These practitioners described daily contact with people who have serious and advanced disease and are part of a team involved with decision making which will have a strong bearing on whether a patient should be listed or remain listed for a liver transplant as well as managing them clinically. My decision to sample in this way was based on a conversation in the context of an unrelated matter where one of the clinicians talked about the phenomenon of knowing patients ‘too well’ and that sometimes it is better not to enter certain personal territory

with patients as it is likely to uncover information which might affect decision making in a way which might bias against the patient (in this case make it more likely that they might be delisted for transplant). The example that was discussed was how adolescents are extensively interviewed prior to transplant listing and are asked about their lifestyle, relationships, recreational drug and alcohol use and medication compliance in great detail. The treating team can at times be pessimistic about the likelihood of successful outcomes in a way that does not apply so strongly to adult patients who may not be required to provide such an extensive account of their lifestyle prior to listing. One team member commented that perhaps it is better not to know 'too much' about patients as this can perhaps lead to negatively prejudicial decision making. This comment led me to consider whether the concept of 'knowing too well' was applicable in this clinical environment and I sought further clarification of this concept. In this environment the clinicians explained that they can form long relationships with their patients and may go through the process of decision making about transplantation with them more than once. The findings showed that there was a perception that whilst it important to get to know the patients, this can also engender risk especially if the clinician has a sense that they feel too close to a patient personally or 'like' them as an individual.

I don't know how it works, but there's a kind of subconscious thing that goes on where you are boundaried at that point right from the beginning because you have to be.
[Transplant_nurse]

The risks included being personally affected when the patient died, potentially leading to 'burn out' and no longer being able to do the job effectively, making inappropriate clinical decisions (usually advocating for the patient to proceed with interventions designed to preserve life when perhaps this was not clinically appropriate) and inappropriate boundary negotiation leading to excessive self disclosure and fostering of unhelpful attachment behaviour on the part of the patient, limiting their adoption of coping strategies in their personal lives.

One of the practitioners commented that decision making processes are different the first time a patient is preparing for a transplant compared to subsequent transplants when the patient is more 'known'. The first time, the decision is based more on biological parameters and statistical

risk of success or failure of the transplant. In later decisions, personal factors about the patient may be more explicitly considered, for instance one clinician described a patient who lived a rather unconventional lifestyle-choosing to live in social isolation in an unheated house and spend much of her time caring for her animals. These factors appeared to count 'against' her when deciding whether to list her for re-transplantation.

One interviewee (the social worker) contrasted her decision making process (based often on months or even years long relationships with her patients) and those of the doctors in the team who would have much less contact with or personal knowledge of the patients,

I'm talking about doctors now, you know, they look at the numbers, they have a score, and they have certain guidelines that says okay, if somebody scored this then they have indications for transplant. And their score is that then they should, you know, then that means they have a more than 50 percent risk of dying within the next year perhaps not having a transplant. So that's a kind of easy decision to make. But what I've found in the past with me is...The judgement was very, very--, made on that feeling sometimes, and how you score people wasn't an objective scoring because how can you score somebody's inside...[Transplant_Social Worker]

She went on to talk about her efforts to become more 'objective' in her assessment of patients, including a strategy of using structured assessment tools,

- | | |
|-----|--|
| INT | That you said you feel that in your role, and the way that you get to know your patients it might be more challenging for you to be objective than--, you compared with perhaps maybe the doctors in the team, or people making clinical decisions being more objective. |
| RES | Yeah. |
| INT | Would you mind expanding a little bit on that? |
| RES | What I mean is that I try now, I've found a way that, I mean I know I've found ways to do it, like using tools that's been developed that give you a more objective, you know, recommendation. |

She then contrasted the findings of her 'gut feeling' assessment and that based on objective tools. She talked about how usually the outcome of the tool confirmed her gut feeling but occasionally it would lead her to change her mind, usually because her 'gut feeling' was based on sympathy with the patient's situation leading her to want to give the patient 'a chance',

I find now that, you know, you--, a lot, or most of the time actually my gut feeling and the objectives tool that I use is actually do correspond, which sometimes that gives you a good warm feeling because you think, oh I'm not too, you know, I can do this.... But I have, yes I have changed, there have been times when I've actually have changed my mind, where you want to give the person a chance and then when you actually

look objectively at all the evidence in front of you, you realise that what you want to do and what is the best thing to do is not the same thing.

Based on the data from these interviews, the theory of the relationship between knowing and approach to assessment style was strengthened by the experience in decision making of practitioners within a different setting and situation describing gut feeling as the predominant mode of decision making when a patient is known well and a conscious return to decision making based on structured procedural assessment when 'knowing too well' is perceived and valued objectivity feels threatened.

4.6 Summary of findings and discussion

The apparently simple model of the relationship between how the patient is known and the mode of decision making leading to determination of capacity for assisted suicide belies an intricate and complex set of interrelated elements that contribute to the sense of knowing, which itself is fed into by an individually contextualised approach to the assessment process. Knowing the patient emerged as a central category during the process of data analysis and exploration of the complex process of getting to know the patient revealed that this is a process contributed to by both the doctor and patient and takes into account the backgrounds and perspectives of both, as well as the intersubjective experience of their interaction.

The approach to the decision on whether a person has the mental capacity to request physician assisted suicide by the individual doctors was informed by a wide set of contextual factors of which views on the legalisation of assisted suicide and the meaning of the dying process were integral. These factors related meaningfully to several other contextual factors, informing the approach to assessment, including the perceived personal and moral consequences of the decision, whether capacity can be presumed, what the standard of competence should be and how mental disorder relates to mental capacity. These views also impacted on how the doctors saw themselves through the eyes of their communities and how they saw their position within these communities if they participated in the process.

Conceptualisation of capacity had a less consistent relationship with level of support for legalisation of assisted suicide, but those who stated strong opposition to legalisation tended to take a broader view of capacity assessment in which the motivation behind the decision would be a key area of enquiry, whereas for those in favour, there was more focus on the process of decision making, perhaps because the outcome of the decision was more consistent with their own value base and therefore less closely scrutinised.

Behind the approach to assessment of capacity for all of the doctors was a sense that a good assessment of capacity should be 'objective' but few of the doctors thought that objectivity would be possible to achieve. Those who discussed strategies for improving objectivity talked about the use of structured tools and using a more protocol driven approach, but this approach created an inherent tension between objectivity and knowing the patient: an intersubjective state which would lead the doctor toward a less objective, more 'gut feeling' based approach to the assessment process, the basis of which might not be amenable to the doctor's own consciousness. The doctors did however appear to be aware of when they were using 'gut feeling' as their mode of decision making and in projecting themselves into the situation of assessing capacity for assisted suicide were able to propose conditions where this mode would feel inappropriate and lead them to revert to structured assessment methods.

5 Situating the Findings within Other Sources of Knowledge: Comparing Perspectives.

In the grounded theory approach, emergent findings are situated within other sources of knowledge and the constant comparative method encompasses comparing these findings with these sources in order to further develop theory from data. In this chapter I will situate my main findings within what I have discovered from primary and secondary analysis of other data and in chapter 6, from the published literature relating to my study findings.

In addition to the study leading to the main findings of this thesis, I have also carried out analyses of other data sources exploring perspectives on assisted suicide using both qualitative and quantitative methodologies. These findings provide context in which I can further examine the findings of the main study and consider how they are situated within the landscape of differing perspectives on assessment of individuals requesting assisted suicide.

In this chapter I will explore the perspectives not just of doctors both in the UK and Oregon, but also other stakeholders in the debate on and practice of physician assisted suicide including other healthcare professionals, legal professionals, representatives of faith, patient and advocacy groups and patients themselves.

By comparing the findings of the main study with these sources I aim to place these within a wider context and demonstrate how this study makes an original contribution to what is known about mental capacity in the context of assisted suicide.

In this chapter I will present the findings of the following:

1. A large UK survey of senior doctors' attitudes to the legalisation of physician assisted suicide.
2. An analysis of perspectives on mental capacity of experts presenting to the 2011 Commission on Assisted Dying.
3. The findings of an analysis of interviews conducted in the US state of Oregon with health and legal professionals on mental capacity assessment for assisted suicide.

4. Perspectives on mental capacity in the recent debate leading to the second reading of the Assisted Dying Bill 2014 in the House of Lords.

I will then discuss the findings from analysis of these data in relation to the findings of the main study.

5.1 Differentiating between the studies and data sources

Throughout this chapter I will refer to the study described in the preceding chapters as ‘the main study’ in order to differentiate it from the sources presented below, which I will identify individually throughout the chapter.

5.2 Placing the sources of knowledge in context

Before presenting the studies and their findings it is important to outline how and when the data were collected and for what intended purpose so that meaningful comparisons can be made between these and the findings of the main study.

5.2.1 Survey of senior doctors’ perspectives on the legalisation of assisted suicide

Data collection and analysis of the data from the survey of senior UK doctors on the legalisation of physician assisted suicide took place prior to the collection and analysis of the data from the main study; however, I have revisited the findings of this survey in light of the findings of the main study in order to make comparisons between the two samples on their views on assisted suicide.

The sample in the main study, although not drawn directly from the survey sample, originated from the survey as described in section 3.6.3.2 and the doctors who participated in the present study were drawn from a very similar population of doctors as that sampled in the survey.¹³

5.2.2 Perspectives of experts presenting to the Commission on Assisted Dying on assessment of mental capacity.

In this study I undertook a secondary analysis of the expert evidence to the Commission on Assisted Dying. This analysis took place concurrently with collection and analysis of data from

¹³ See Appendix 12: Published papers (1 and 2)

the main study and the findings have since been published¹⁴. In presenting selected findings of the study in this chapter I have attempted to identify and focus on areas where I can make direct points of comparison between those and the findings of the main study.

5.2.3 Interviews with Oregon health and legal professionals on mental capacity assessment for assisted suicide

This is the only study presented in this chapter where the data were gathered with the primary intention of specifically exploring mental capacity assessment for patients requesting physician assisted suicide. These data were collected approximately one year prior to initial data collection for the main study, and as described in section 3.5.1, initial reading of this data provided valuable sensitising concepts that helped me to begin shape my inquiry when planning the topic guide for the interviews conducted during the main study. After completing analysis of data for the main study however, I returned to the Oregon interviews and considered them further in light of the emergent concept of contextualised knowing described in section 3.6.6.5, and it is this analysis that I present below.

It should be made clear at the outset though that the interviews with Oregon stakeholders were conducted as a part of a fact finding trip during the planning phase of my main study and the data were not gathered according to any specific methodological framework. Although the interviewees were all medical or legal professionals, and were aware that the interviews formed part of a wider PhD project and gave permission for audiotaping and subsequent analysis of our conversations; there was no formal ethical approval given for this portion of the project. I have been careful to use the same ethical standards with these data however and have maintained the anonymity of the subjects of these interviews as with the subjects participating in the main study. The findings from the Oregon interviews do not form a piece of research in their own right, but in accordance with the principles of a grounded theory approach, have been used to situate the findings of my main study in a broader context.

¹⁴ See Appendix 12: Published papers (3)

5.2.4 House of Lords debate on the Assisted Dying Bill

Finally, the House of Lords debate leading to the second reading of the Assisted Dying Bill 2014 took place in July 2014 after analysis of the data for the main study was completed. I will therefore present an analysis of the Peers' perspectives on mental capacity as a safeguard in the Bill and focus on how the findings of this analysis compare with the findings of the main study.

5.3 Survey of Senior Doctors' opinions on the legalisation of assisted suicide

The following sections present the findings of a large national representative survey of senior doctors' opinions of the legalisation of assisted suicide. The data collection for this study took place in 2007-2008 and the findings were published between 2009 and 2011.

5.3.1 Senior doctors perspectives on the legalisation of physician assisted suicide

In 2007-2008, in the aftermath of the Bill unsuccessfully presented by Lord Joffe in 2005, 1000 senior medical consultants from various specialties in UK practice were surveyed to ascertain their views on the legalisation of assisted suicide for the terminally ill (Lee et al., 2009)¹⁵. The corrected participation rate (after exclusions from the denominator e.g. due to retirement or deregistration) was 50% with 372 respondents.

The survey showed that views on legalisation of assisted suicide were divided, with 39% stating agreement with a change in the law, 49% stating opposition and 12% neither agreeing nor disagreeing with a change. Among the sample, doctors who cared most frequently for the dying were least likely to agree with a change in the law, as were those who identified themselves as most religious. Gender, age and years in specialty had no significant effect.

5.3.2 Senior doctors' perspectives on rational suicide

As part of the same survey, the doctors were asked to respond to the statement 'suicidality cannot be rational under any circumstances' by selecting a point on three point scale comprising 'agree' 'neither agree or disagree' or 'disagree'.

¹⁵ See Appendix 12: Published papers (1)

The findings showed that within the sample 72% agreed that suicide could be rational, 17% disagreed and 11% neither agreed nor disagreed. A belief in rational suicide was negatively associated with intensity of religious belief and doctors who approved of physician assisted suicide were more likely to agree that rational suicide was possible than those who did not (86% vs 66%) (Ginn et al., 2011)¹⁶. Rational suicide was a concept endorsed by the great majority of the sample however, and contrasted with the more divided views on the acceptability of the legalisation of physician assisted suicide.

5.3.3 Senior doctors' perspectives on the influences on their views on the legalisation of physician assisted suicide.

In the same survey, the doctors were asked whether they thought their attitudes to physician assisted suicide (PAS) and voluntary euthanasia (VE) were influenced by their religious beliefs and were invited to explain this in a free text section (unpublished data).

The question received 122 responses; with 80% of the respondents (98/122) believing that their attitude to physician assisted suicide was influenced by their religious beliefs. Of those, 28 (29%) agreed with a change in the law whilst 65 (66%) were opposed.

Of the 122 who responded to the survey question, 109 (89%) also added a free text response.

On thematic analysis of the 109 responses, 11 subthemes emerged. These were grouped into 3 main themes: religious influences, non-religious influences and mixed influences.

The self-reported influences on the doctors' thinking about assisted dying practices were wide and covered a number of domains including religious belief. Respondents described several facets to the way they had been influenced by religion both in their early lives and in their current beliefs and practices.

Exposure to religion during childhood and in family and school life continued to consciously influence the thinking of many respondents although others had eschewed these influences in adulthood and felt that later experiences during medical school, whilst practicing medicine and

¹⁶ See Appendix 12: Published papers (2)

in their personal lives had a greater influence on their current views. The respondents who cited religious beliefs as influencing their current views conceptualised this in individual ways and the interpretation of these beliefs corresponded with some respondents' decisions to oppose legalisation of assisted suicide and others (although fewer in number) to support it. A number of respondents who supported physician assisted suicide cited exposure to religious customs in their early life and stated that whilst these were still an influence on their lives in some ways, their support of physician assisted suicide was in contradiction to this religious exposure, and that to reach this position they had found it necessary to reach a compromise between the influences of their religious upbringing and influences from elsewhere, particularly those who cited Judeo-Christian or Muslim religious influences.

Even amongst those who did not cite religion as an influence, belief in the sanctity of life featured strongly in personal ethical arguments against physician assisted suicide legislation. Several respondents cited multiple influences and experiences which were relevant to their current views about assisted dying legislation.

Exploration of the self-reported influences on views on assisted dying legislation revealed a range of influences including exposure to religion, current religious belief and following of religious teaching. Religious influences did not lead exclusively to opposition to assisted dying legislation, and for some their beliefs were compatible with support. Among those for whom religion was not cited as an influence, personal morality, medical education and experience were cited as influences for many and these were compatible with both support and opposition for assisted dying legislation. Table 10 below shows example responses grouped by theme and divided by support or opposition of the legalisation of physician assisted suicide.

Table 10: Self-reported influences on attitudes to physician assisted suicide and level of agreement with a change in the law

Theme	Subtheme	Example responses	
		Disagrees with a change in the law	Agrees with a change in the law
Religious	Exposure to religious customs – Education	Concepts and moral beliefs are deeply ingrained. The result of early education (when I had religious beliefs). [Male histopathologist, Other Christian]	At school was C of E [Male radiologist, no religious affiliation]
	Exposure to religious customs - Upbringing	I had a Christian upbringing; inevitably it will have had an influence on my thinking. [Male GP, no religious affiliation]	Brought up C of E; Methodist and Presbyterian influences. I'm sure these influenced my judgment despite non belief now. [Female psychiatrist, no religious affiliation]
	Religious Belief	Traditional' Judeo-Christian views re: sanctity of life [Female GP, Church of England]	I consider 'religion' to be a belief in an 'afterlife' of some kind and a moral or humanitarian code, this can be very individual and not covered by the umbrella of orthodox religion. It does however profoundly influence my thinking but at the same time one has to be pragmatic and understand the limitations and realities of the world in which we live. [Male GP, no religious affiliation]
	Religious law or teaching	As a Catholic I am influenced by my advice from the Church - and my views broadly match, although perhaps not completely. [Male surgeon, Roman Catholic]	Religious teachings are examples of behaviour to be aspired to in many ways [Female GP, Church of England]
Non-religious	Humanitarian concerns	My views on VE and AS are influenced by humanitarian issues rather than religious [Male GP, Church of England]	
	Medical education and	I believe my attitudes are influenced by my dealings with patients over 30 years with NHS, and whilst	More influenced by personal and medical experience as Christian teaching in this area seems unclear.

Theme	Subtheme	Example responses	
		Disagrees with a change in the law	Agrees with a change in the law
	practice	sometimes I deal with people in great distress it is not my position to end their life. I am happy to make them as comfortable as possible. [Male GP, no religious affiliation]	[Female public health physician, Church of England]
	General life experience		My attitudes are a product of my life experiences which includes 'the spirited' or the non-material as part of the whole of life [Male psychiatrist, no religious affiliation]
	Personal experience of suffering or death	I watched my 33 year old husband die.....8 years ago and faced these decisions as he was in relentless unremitting pain and I have still answered as I have. [Female GP, other Christian]	They are influenced by my experiences of dying patients and relatives. [Female GP, Church of England]
	Personal morality or ethics	I do not consider that they are influenced by my religious beliefs but rather by my moral code and inherent beliefs in right and wrong and what feels uncomfortable with my psyche. I would say that these beliefs run deeper than my religious beliefs. [Female physician, Church of England]	No - ethics - I think they are different BUT morality/ ethics do have some beliefs that are faith based for me. [Female GP, Church of England]
	Societal rules		More by the rules and morals which govern our society [Male GP, Church of England]
Mixed	Multiple influences	One is influenced by one's upbringing, family, society, spirituality, experience. I cannot divorce any one of these elements from who I am and how I think and act. [Male GP, Muslim]	

The findings of this study show that the doctors' self-reported perspectives derived from individual contexts based on a range of personal, professional and moral influences, some of which had a grounding in religion.

5.3.4 Summary

The key findings of the survey of senior doctors' opinions of the legalisation of assisted suicide were that views were divided: those who were more religious and cared for the dying more frequently were more opposed to legalisation and there was no effect by speciality in level of support for legalisation. The majority of the respondents however thought that rational suicide was possible. Multiple influences on opinions on legalisation of assisted suicide were cited by the respondents and both religious and non-religious influences were compatible with both support for and opposition to legalisation. The findings of the main study echoed these in most ways; however the GPs in my sample appeared to support assisted suicide more than the other doctors. This sample was not intended to be representative of the population however, so no further conclusions are drawn from this finding.

Ideas about the rationality of the request for assisted suicide demonstrated in the survey were echoed in the main study, with several of those who did not support assisted suicide doubting the rationality of such a request and those in support mainly thinking of the choice of assisted suicide as potentially rational. In the main study the doctors' views on rationality of the request impacted on their approach to assessment of capacity with a process of 'checking' for those who supported assisted suicide as a rational choice, and a process of 'making sure' for those who doubted that the decision could be rational.

The factors influencing attitude to physician assisted suicide were wide ranging and individually interpreted on both studies. The survey asked the respondents directly what they thought were the influences on their views, whilst the main study ascertained the doctors' views partly by eliciting them explicitly when appropriate, but more often by analysis of the way they discussed their approach to assessing patients. Whilst the survey did not address mental capacity assessment specifically, there are several parallels between the findings of the

survey and the findings of the main study in terms of identifying individual contextual factors and unique perspectives leading to support for or opposition to assisted suicide. The main study took this identification of individual perspectives a stage further than the survey, however, and examined how these influences impacted upon approaches to assessment of capacity and potentially shaped decision making.

5.4 Expert submissions to the Commission on Assisted Dying

As discussed in section 2.2, the Commission on Assisted Dying, hosted by Demos and chaired by Lord Falconer, heard evidence from a number of invited experts before coming to the conclusion that physician assisted suicide should be legalised. It concluded that (and entitled their report with the phrase), ‘The current legal status of assisted dying is inadequate and incoherent’(DEMOS, 2012).

The following study used framework analysis of the oral and written expert evidence presented to the Commission to explore how these experts conceptualised mental capacity for patients requesting assisted suicide particularly in relation to the Mental Capacity Act 2005 (Price et al., 2014)¹⁷.

There are limitations both to the data and the analysis of the data, which qualify the findings. Although the Commission invited a range of experts representing differing views on physician assisted suicide to give evidence, a number who opposed the legalisation of assisted suicide declined to attend because it was known that the Commission had been funded by two individuals who are publically strongly in favour of the legalisation of physician assisted suicide including the author Terry Pratchett. The perspectives of the sample of experts were therefore potentially somewhat skewed in favour of physician assisted suicide and unlikely to represent the full range of views held, for example there were very few hospice or palliative care professionals represented amongst the experts. The data were also not gathered for the purpose of examining views on mental capacity assessment for patients requesting physician

¹⁷ See Appendix 12: Published papers (3)

assisted suicide and the experts were not aware at the time of presentation that the data would be analysed in this way, so the experts' views on mental capacity were explored as a secondary analysis of the existing data. A potential advantage of this however is that the experts' 'naturalistic' perspectives on mental capacity were likely to have been presented, the disadvantage being that they could not be further explored.

Thirty seven interviews with 50 experts were video recorded and transcribed and made available on the Commission website (Commission on Assisted Dying, 2012). In addition, 13 pieces of written evidence were submitted and published alongside the oral evidence. Two of the authors of this study (AP and MH) submitted one piece of written evidence (Hotopf, 2011) and gave oral evidence to the Commission (DEMOS, 2011). These two pieces of evidence were excluded from analysis; therefore the sample comprised 36 transcripts of oral evidence and 12 pieces of written evidence. The data were analysed using a framework approach.¹⁸ The quotations presented in the following sections are denoted by a number that can be cross referenced to the table of experts presented in the paper found in appendix 12 (3).

The 36 oral and 12 written submissions included evidence given by a wide range of experts including, 12 medical and social care professionals, eight legal professionals, two persons with disability, four current and former carers/family members, seven academics, three faith group leaders, nine representatives of advocate groups and seven representatives of professional bodies. Of the 15 organisations represented at the Commission, four stated a position in favour of a change in the law to allow assisted suicide, two stated a position against, one stated a position of neutrality and eight did not state a position. Of the clinicians giving evidence, three had specific mental health clinical training (one consultant psychiatrist and two clinical psychologists).

Of the 36 oral evidence submissions, 33 included some reference to mental capacity or issues related to assessment of mental capacity.

¹⁸ For a detailed description of the methodology see Appendix 12: Published papers (3)

All of the experts who discussed mental capacity in their submissions thought that it should be a central safeguard for any proposed assisted suicide legislation and that this should be determined at the time the request is being made.

The following sections focus on the findings in four specific areas 1) Definition and conceptualisation of capacity, 2) Presumption of capacity 3) Whether the Mental Capacity Act 2005 is the appropriate framework for assessment of capacity for assisted suicide, and 4) The impact of the doctor patient relationship upon the capacity determination process.

5.4.1 Definition and conceptualisation of capacity

The findings from the study of the expert submissions to the Commission on Assisted Dying showed that there were a number of definitions of capacity offered for example, being 'of sound mind' and 'a settled wish'.

Conceptualisations of capacity were found to be on a spectrum with a tightly defined intellectual or cognitive conceptualisation at one end and a broader, more holistic conceptualisation involving a number of potential components including voluntariness, motivation and rationality at the other.

5.4.2 Impact of mental disorder on capacity determination

Within the expert submissions there was a widely held opinion that determining the point at which mental disorder, specifically depression, impaired mental capacity for assisted suicide was particularly difficult. Normative values about the expectation of depression at the end of life were expressed by several of the experts and views ranged between the opinion that depression was only likely to impact on capacity at its most severe, (if the standard by which capacity is judged is at the cognitive/intellectual pole), through to the presence of depression at any severity having the potential to impact negatively on capacity.

5.4.3 Presumption of capacity and the appropriateness of the Mental Capacity Act 2005 for assessment of capacity for terminally ill patients requesting suicide.

Among the experts presenting to the Commission the issue of presumption of capacity was only discussed in 14 of the 33 interviews but of these, the majority stated that they would

presume capacity or were unclear about whether they would presume capacity, with only two stating that they would not presume capacity.

Of the five experts presenting to the Commission on Assisted Dying who stated explicitly that they would presume capacity, two stated that they would envisage capacity being assessed using the Mental Capacity Act 2005. Of the two experts who stated that they would not presume capacity, one stated explicitly that they would envisage capacity being assessed using the Mental Capacity Act 2005 (see Table 11).

Table 11: Conceptualisation of capacity by experts presenting to the Commission on Assisted Dying

		Presumption of capacity				Total
		Yes (%)	No (%)	Unclear (%)	Not discussed (%)	
Mental Capacity Act	yes	2 (22)	1 (11)	6	2 (22)	9
	no	1 (100)	0 (0)	0 (0)	0 (0)	1
	unclear	1 (33)	0 (0)	2	0 (0)	3
	Not discussed	1 (5)	1 (5)	18	17 (85)	20
	Total	5 (15)	2 (6)	7 (21)	19 (58)	33

None of the clinicians presenting to the Commission stated that they would not presume capacity to request physician assisted suicide and most were either unclear or did not discuss the issue (see Table 12).

Table 12: Presumption of capacity by professional background among experts presenting to the Commission on assisted dying

		Presumption of capacity			Total
		Yes (%)	No (%)	Unclear/Not discussed (%)	
Professional background	Clinician	1 (13)	0 (0)	7 (87)	8
	Other	4 (16)	2 (8)	19 (76)	25
	Total	5 (15)	2 (6)	26 (79)	33

Of the nine experts presenting to the Commission who stated that they thought the use of the Mental Capacity Act to be appropriate, one was a clinician (a member of Healthcare Professionals for Assisted Dying HPAD). The majority of experts, both clinicians and non-

clinicians did not discuss whether the Mental Capacity Act was a suitable legal framework for assessment of capacity for patients requesting physician assisted suicide (see Table 13).

Table 13: Support for use of the Mental Capacity Act by professional background among experts presenting to the Commission on Assisted Dying

		Support for use of the Mental Capacity Act 2005			
		Yes (%)	No (%)	Unclear/Not discussed (%)	Total
Professional background	Clinician	1 (13)	0 (0)	7 (87)	8
	Other	8 (32)	1 (4)	16 (64)	25
	Total	9 (27)	1 (3)	23 (70)	33

A number of the experts cautioned against taking a request for physician assisted suicide at face value and talked about the capacity for change in the face of adversity,

‘We’ve all been down this road, well I’ve been on this road, many times, where you think ‘oh, I wouldn’t want to go on and I wouldn’t want to do this’ and then suddenly you’re in that position, and you think, ‘yeah, I can just about manage this because the positives are better than the negatives.’ So we all change our positions over a lifetime, and that’s why I think the end of life debates, discussions and the way in which we frame this, have to be about a constant conversation...’ (8)

Some suggested a role for the clinician in facilitating and guiding the patient through this process of adaptation rather than facilitating their wish to die at the outset of this process,

‘...the onset of impairment releases huge angst at the loss of capacity and function; and that at that time we need protection from ourselves, but those times will pass’. (23)

An alternative to this view was that legislation for physician assisted suicide would in itself facilitate the process of adaptation by providing a notional end to suffering that would probably not be utilized,

I also am of the view, by the way, that if we did actually make legislative provision, I don’t think actually many people would take it up. I think actually more people would be comforted that it was there than actually take it up. Because I think there’s a difference between the prospect of living through suffering and when you actually get there. And the interesting thing is, I think there’s a demand, if you like, because of the prospect of suffering, but actually when people get there, I think many of them would actually, as you say, not abandon the journey, but actually take the

journey with them. And I think some of them, ironically, would take the journey better with them if they knew there was a point at which they could say, before they were too unable to consent, 'yes I've had enough.' (26)

Those experts who expressed views that opposed legalisation of assisted suicide tended to conceptualise a request for assisted suicide as an expression of distress that could be potentially ameliorated with a resulting reversal of the ongoing wish for assisted suicide.

5.4.4 Capacity determination within the doctor patient relationship

Within the expert submissions to the Commission, there was some discussion of how the nature of the clinician patient relationship might impact upon assessment of the patient requesting assisted suicide, with several experts advocating that that this relationship would ideally be between a doctor and their patient,

'I mean physicians would be best qualified to say what other factors might be taken into account, physically and mentally' (12)

Some suggested however that nurses, psychologists or social workers could also be the best people to assess mental capacity specifically, or perhaps a multidisciplinary team,

'This is personal judgment; it is professional judgment that we are coming down to. But that's why the idea of having people from different professions coming together to provide some checks and balances and some professional challenge to each other as to how this can work - that is the sort of process that we were envisaging'. (16)

There was support for a long term trusted doctor patient relationship being the best structure in which to assess mental capacity,

'...so that could include a General Practitioner, if they have a longer term relationship with the individual and family....'(3)

There was some expression of concern though, that the nature of the modern GP-patient relationship might not support the 'optimal' capacity assessment based on good longitudinal knowledge of the patient. One expert compared the GP-patient relationship between the UK and the Netherlands,

'In particular the one aspect that I think is really significant in the Dutch system which isn't the case here, necessarily, is that Dutch people tend to have quite lengthy relationships with their GPs. And it's often the GP who is providing end of life care, and I think if you've know someone for 40 years then your ability to assess

their capacity and voluntariness is much better than if you've known someone for two clinic appointments in the last year. So we should be wary of simply transposing that system to our system when we don't have that kind of relationship'. (34a)

Psychiatrists were proposed by several experts as the appropriate professionals to provide an expert opinion on capacity,

'...we envisage the law would include requirements for referral to another expert (such as a psychiatrist) or an expert body, in cases where there were doubts about the patient's capacity' (9a)

with a mixture of views about the idea of mandatory psychiatric assessment, with some expressing their support e.g.

'We think that it is quite possible that any legislation going forward would perhaps make a psychiatric consultation a necessary thing that everyone has to go through who is considering this'. (25a)

And others opposed to this idea on grounds of paternalism,

'...we are appalled by any suggestion, which I know has come up in some of these hearings, that a psychiatric consultation should be a necessary part of the process for everyone. That takes us right back to the days when any patient who decided to refuse medical treatment was suspected of having a mental disorder'. (4)

There was also some expression of concern about the impact of the individual clinicians' communication ability upon the quality of an assessment,

'...what crosses professions is individuals' personalities. And you have some doctors...who might be much more comfortable having some of these conversations than actually some psychologists. And I do think personality crosses the professional divide' (3)

and that doctors' views on assisted suicide might impact upon the stringency of criteria for capacity determination,

'...how high you would put the bar, and somebody who is sympathetic to the person's degree of suffering or situation may inadvertently reduce that bar a little bit or be more sympathetic to it, and somebody who's completely opposed to it may set the bar higher'. (7)

Beyond the idea that the 'best' situation to assess capacity was within a trusted and ideally longitudinal clinician patient relationship there was no further elaboration of how this relationship would impact upon the capacity determination process.

5.4.5 Summary

In comparing the findings between this and the main study, the range of views on its definition and conceptualisation show that mental capacity is not a unitary concept. Its definition is elusive and its conceptualisation and application may vary between clinicians and situations, even when considered within the framework of the Mental Capacity Act 2005.

In their submissions to the Commission, a number of the non-clinicians (who comprised the majority of experts) deferred to doctors (and in particular psychiatrists) to provide guidance on how best to assess capacity. The findings of the main study show, however, that like the data from the Commission there is wide variation in how capacity is conceptualised even among a group of doctors selected because of their experience of working with those with terminal illness or their professional training in assessment of capacity. This suggests that there would likely be a wide variation in how capacity assessment is approached and assessment carried out by clinicians should physician assisted suicide be legalised.

The difficulty identified by the experts in determining the impact of depression on capacity was reflected in the findings of the main study with a range of views expressed on how mental disorder might impact on capacity and the appropriate response to mental disorder when identified. The experts presenting to the Commission mainly talked about the impact of depression on capacity, but the doctors in the main study (particularly the psychiatrists) were equally concerned about how personality disorder might impact upon capacity. They were especially unsure about how to respond appropriately to a terminally ill patient with a diagnosis of emotionally unstable personality disorder requesting assisted suicide, concerned that perhaps they were unconsciously seeking a response affirming ongoing life, despite an apparently settled wish to die.

The Commission identified psychiatrists as the experts who would be best placed to diagnose depression and determine whether it was impacting upon capacity for assisted suicide as part of the process of safeguarding. In the main study though, although the non-psychiatrists identified the psychiatrists as the specialists best placed to determine the point where depression impacted upon capacity, the psychiatrists themselves found the interface between depression and capacity in this situation as difficult a concept to consider as the other doctors in the sample. Their view on where the interface might impact on capacity was as informed by their broader views on assisted suicide as the other doctors.

In comparing the findings between the study of evidence given to the Commission and the main study, the key similarity was that those who stated that they would both presume capacity and use the Mental Capacity Act as the framework for assessing capacity were all in support of a change in the law to allow physician assisted suicide.

The key difference was that in the main study, compared with only 2/33 experts presenting to the Commission, a third of the doctors explicitly stated that they would not presume capacity for the decision and the majority of that group comprised General Practitioners.

The Commission report is clear that it conceptualises capacity in accordance with the Mental Capacity Act 2005 but further advocates a very thorough process of formal assessment of capacity for every patient requesting physician assisted suicide. The proposed approaches of the experts presenting to the Commission appeared to be related at least in part to their level of support for legalisation of physician assisted suicide and like the doctors in the main study, the experts presenting to the Commission expressed their individual ideas about the meaning of a request for assisted suicide.

In comparing the two sets of data there is some consistency between the ways in which level of support for assisted suicide impacts on ideas about the meaning of a request for assisted suicide and the approach taken to the assessment of capacity. What was not reflected in the data from the Commission on Assisted Dying was the more in depth sense of how the

relationship between the individual clinician and their patient might impact on the process and outcome that was seen in the findings of the main study.

What emerged in analysis of both of these datasets is that there was no unified view on how capacity should be conceptualised either legally or clinically and that views on legalisation of physician assisted suicide, whilst having a variable relationship with conceptualisation of capacity, did seem to impact more systematically upon approach to assessment. Those supporting legalisation tended toward the assumption that the principles and structure of current Mental Capacity legislation will provide a satisfactory framework for capacity determination, while those who were less in favour either used the terminology of the Mental Capacity Act but didn't subscribe to its principles, or rejected it as providing sufficient ability to provide a sufficient safeguard.

The ideal of the long term trusted doctor patient relationship was highlighted as important by the experts, but concern was expressed about whether our health systems were able to support this type of relationship within the context of physician assisted suicide assessments. The importance of knowing the patient echoes with the findings of the main study as does the concern that this type of relationship may not be possible within current ways of working, although the experts did not talk about the possible pitfalls of 'knowing too well' identified by the doctors in the main study sample.

5.5 Exploring capacity assessment for patients requesting assisted suicide through in depth interviews with Oregon stakeholders.

As described briefly in Section 3.5.1, in 2009 I travelled to Portland, Oregon to meet with individuals involved in physician assisted suicide both from a research and clinical perspective. My main objective in visiting Oregon was to explore perspectives on mental capacity for terminally ill adults requesting assisted suicide from the point of view of professionals working in an environment where this practice is legal, and to use the insights gained to inform my exploration of mental capacity for assisted suicide should this be legalised in England and Wales.

During the trip I stayed in the capital, Portland and visited the Oregon Health and Sciences University (OHSU) comprising the University and the University Hospital, the Portland Veteran's Affairs Medical Center, a local hospice, and the headquarters of 'Compassion and Choices of Oregon' (Compassion and Choices of Oregon, 2014) an organisation which 'provides support, education and advocacy needed by persons with a terminal illness to face the end of life with courage and grace and to achieve a humane and peaceful death' and supports people exploring their options at the end of life, including physician assisted suicide. Compassion and Choices of Oregon also provide support and advice to clinicians who are involved in the process of assessing patients requesting physician assisted suicide and provide initial assessments of individuals who approach the organisation directly, subsequently arranging the appropriate medical assessments. According to the organisation's chief executive, the majority of patients who complete physician assisted suicide are known to the organisation during the assessment process. It should be noted that in Oregon the practice is called 'assisted dying', rather than physician assisted suicide as the Oregon statute makes a legal distinction between the two, meaning that there is an exemption from formalities such as autopsy after death unless there is a specific need for this.

During the course of the visit I audiotaped conversations with four of the individuals I met and had informal conversations with several others during the course of my stay. The interviewees were identified, contacted and introduced to me via a key contact who has published widely on the interface between mental disorder, mental capacity and physician assisted suicide in Oregon. All those I interviewed have been involved in assessment of terminally ill patients requesting physician assisted suicide under the DWDA at various stages along the assessment pathway, from initial enquiry through to completion of suicide.

The interviews were conducted prior to commencing recruitment of the main study sample, so the interviews and visit, along with my reading of the literature to that point provided me with initial *sensitising concepts* which I was able to explore further within my study.

After data analysis for the main study had been completed and the core category of knowing had emerged, I revisited my Oregon interviews from a more deductive standpoint to look again at how knowing the patient was represented in the interviews, as this had not been my main focus prior to conducting the main study. The insights gained from the visit and interviews also provided a point of comparison, both between the differing political, population and healthcare contexts but also between *pre* and *post* legalisation groups to look at how knowing perspectives might be affected by practice and experience.

5.5.1.1 Setting the scene: placing the interviews in context

The findings of the main study showed that assessment of mental capacity to request physician assisted suicide is a contextualised phenomenon and a significant part of this context, whilst implicit for the doctors in my study and therefore little discussed, is the prevailing political and healthcare climate. To make meaningful comparison between the findings of my study and the findings from analysis of my interviews in Oregon, it is necessary to provide some contextual background.

Oregon is the 9th largest state of the 50 states in the US, situated in the 'Pacific northwest', and was the first US state to legislate for physician assisted suicide. It has a total population of just under 4,000,000 (United States Census Bureau, 2014a) and is the 39th most densely populated US state with over half of the population living in the capital city, Portland. Substantially larger in area than England and Wales, its total population is far outstripped by that of London alone. Much of Oregon is rural and has a substantial agricultural community. Politically, Oregonians have consistently voted for Democrat representation over the last few decades, with Portland in particular leaning toward liberal ideology. It is one of three US states to have legalised physician assisted suicide for the terminally ill to date.

The US has a federal system of government with a substantial authority delegated to its regional governments in the 50 states that comprise the nation. The health care system reflects this delegation, with regulation shared between the federal and state levels.

Healthcare is mainly paid for by insurance either privately or via employer contributions, and

these insurance policies are provided by either by federal public sector insurers such as Medicaid or Medicare, or commercial private sector insurers, although 1/6 of the population lacks health insurance (United States Census Bureau, 2014b). Private sector insurers comprise Health Maintenance Organisations (HMOs) such as Kaiser Permanente, and Preferred Provider Organisations (PPOs) who purchase care from physicians and other healthcare professionals. Insured individuals usually have a primary care provider who then makes referrals to specialists when needed, but uninsured individuals are more likely to use community health centres or attend the accident and emergency department for their health needs. The US has undergone some health reform in recent years and the implementation of the Patient Protection and Affordable Care Act (2010) in 2014 is likely to increase the proportion of the population with health insurance coverage.

The US health system(s) are radically different from the National Health Service (NHS) in England and Wales in which individuals contribute to their healthcare through a system of National Insurance. Whilst individuals can opt to purchase private insurance in order to access their healthcare through the private sector, NHS healthcare is open to all and is 'free at the point of care'. The majority of NHS health care is provided through nationally funded services although the introduction of internal competition via the 'purchaser provider split' in 1991 and subsequent NHS reforms have meant that most health services are purchased by local commissioning bodies currently known as Clinical Commissioning Groups (CCGs), and the resulting collections of purchasers and providers are collectively known as local health economies.

The administration of the law in Oregon permitting physician assisted suicide for the terminally ill therefore operates in a very different healthcare context than would such a law in England and Wales and this is reflected in some of the findings from analysis of the Oregon data.

5.5.1.2 Characteristics of the sample

The sample comprised a physician, a nurse, a psychiatrist and a lawyer, two female and two male, all based in Portland, where the three clinicians all worked within the general hospital

system. All of the clinicians had been involved with evaluating patients requesting physician assisted suicide and all had been practicing in their various specialities since before the DWDA was passed and involved with evaluations of patients requesting physician assisted suicide since that time. The lawyer had been very involved with the process of legal change to allow physician assisted suicide in Oregon and at the time of interview was involved with administration of the DWDA via Compassion and Choices of Oregon.

5.5.1.3 Perspectives on mental capacity in the DWDA assessment process

The following sections explore the Oregon interviewees' perspectives on mental capacity assessment for terminally ill adults requesting physician assisted suicide. Firstly I will explore their views on the importance of mental capacity determination within the assessment process and approach to capacity assessment. I will then look at the place of knowing the patient in capacity determination and show that experience of assessing these patients and working within a system where physician assisted suicide is legalised has an impact on how patients are 'known'. I will then show how the perceived sense of knowing the patient in the Oregon sample impacted upon the approach to assessment, and that the possibility of 'knowing too well' is evident in the Oregon interviews but is more widely conceptualised than in the main study, with differing perceived risks compared with this study. Finally I will explore perceived barriers to knowing.

5.5.1.3.1 Response to the introduction of the Death With Dignity Act

The interviewees described how the introduction of the DWDA had come as a surprise initially as it had been voted in by a narrow margin against expectations. They talked about how clinical processes had to be developed quickly to meet the legal safeguarding requirements,

So the sort of laser beam hit my desk and suddenly I had to become an expert and understand it because my job would be to make sure that doctors did it right.
[Oregon_Nurse]

Within the small sample a range of self-identified personal perspectives on the legalisation of assisted suicide were expressed from support to ambivalence; however none of the interviewees were openly opposed to physician assisted suicide for the terminally ill. All had taken a role in assessing patients requesting physician assisted suicide although this role was perceived in various ways, for example the nurse in the sample described it as a privilege and a 'sacred duty' whilst the psychiatrist admitted reluctance to participate in assessment of these patients. Another talked about the profound emotional effect involvement in the process had had on him, particularly in relation to one case,

I don't think there's an easy answer, and there wasn't, I mean, clearly we struggled with this and that happened ten years ago, so I clearly still struggle with it
[Oregon_Physician]

5.5.1.3.2 Importance of mental capacity determination

All of the interviewees thought that mental capacity determination was an important part of the DWDA assessment process but there were different individual perspectives on when this should be done, who should assess capacity and whether psychiatric assessment should be mandatory. Concerns were expressed about the reliability of mental capacity determination particularly by the psychiatrist, who expressed reluctance to be involved in mental capacity assessment of these patients due to her opinion that mental capacity is a social construct,

...by definition, it's in a social construct that has to do with our beliefs about what's right and wrong, and those beliefs are contextual in this time period, understanding our culture. Does that make sense? [Oregon_Psychiatrist]

and that her conclusions would therefore be influenced by her personal value base,

And I've done a bunch of these evaluations and I'm not comfortable doing them because this sense that at the end I'm imposing a value system on people....and I think the answer you get always ends up reflecting your moral views.
[Oregon_Psychiatrist]

5.5.1.3.3 Approach to assessment of capacity

The awareness of the patient's proximity to the end of their life appeared to inform the approach to assessment, with a wish to be as 'light touch' as possible.

See, that's the other thing that's going on at the same time. This person has a terminal illness. Whether they have a mental impairment of some type simultaneously with this terminal illness, one of them is going to get them *[laughs]*. [Oregon_Lawyer]

To be frank, just off the top of my head, the patient is terminal, they qualify, so I'm not saying any physicians choose to go behind the veneer and look at where the patient is coming from [Oregon_Nurse]

This sensitivity appeared to impact upon the standard applied for capacitous decision making,

...but for those who are just on the border, what would we do? Would we talk them out of it? Is that what we want to do? We don't want to talk them into taking their life, but should we talk them out of it when they're already dying and they have a way to leave, as people say, more gently? And so if they're slightly within incapacity, or just a bit equivocal, then do they have to endure their life because of that until the end, when if they qualified, they could hasten their death if they chose to and not have to experience the end? [Oregon_Nurse]

5.5.1.3.4 Conceptualisation of mental capacity

Within the sample, various conceptualisations of mental capacity were evident; for example the physician in the sample orientated his assessments toward determining that the patient was making an informed decision,

I think it's important for them to be able to understand what they're asking for, to understand the alternatives. I think in terms of just a simple informed decision making process, I think it's important to fulfil those requirements [Oregon-Physician]

Whilst the nurse conceptualised mental capacity according to a broader notion of autonomy,

But we look at the patient's autonomy, but have to be sure that by every understanding of what capacity is, do they have the true capacity, the free will, to allow themselves to have self-deliverance and to understand that they're hastening their death before their natural death comes. [Oregon_Nurse]

She was critical of what she perceived as a more cognitive test of capacity performed by the doctors,

Some of the psychiatrists that we have here, they're so busy, so if we want them to come and tell us whether a person has capacity or not, they get angry about that because, 'The doctor can say whether they have capacity. Do they understand risks and benefits? No, then they don't have capacity.' [Oregon_Nurse]

The psychiatrist in the sample was undecided between a test based on a tightly defined 'cognitive' conceptualisation of capacity and a broader, more holistic conceptualisation,

Should it be just decision-making capacity, the patient understands what the nature of what they're doing, the risk benefits and alternatives, they can apply it to themselves, they have a set of rational reasons, or should it include this assessment about mental disorders affecting things? So people with major depressive disorder can understand the risk benefits and alternatives and use logical decision-making, but it's imbued with this hopelessness and this sense of no possibility of good life left, that if you treated them, they might change their mind. So this extra assessment of is there a mental disorder that's influencing the decision, which is not always the same as decision-making capacity. [Oregon_Psychiatrist]

5.5.1.3.5 Knowing the patient and capacity determination

Knowing the patient was identified within the Oregon interviews as an important factor in the process of capacity assessment. As in the main study, knowing was conceptualised within the clinician-patient relationship with a shared understanding that this was contextualised by a number of individual factors that might impact upon capacity determination. Unlike the findings of the main study however, the sense of knowing the individual was strongly influenced by a sense of accumulated knowing of the 'typical' patient, which had been built up experientially over time. This sense of accumulated knowing led the clinicians to make judgements on individuals' capacity informed at least in part by pattern recognition from previous assessments.

5.5.1.3.5.1 Knowing the individual

Knowing in this context was primarily conceptualised as having an understanding of the patient's enduring values and way of life and how these fitted with their current views on their situation.

Getting to know the individual patient to facilitate the process of capacity assessment was thought to be important for practitioners who did not already have a relationship with the patient they were assessing. One interviewee likened getting to know as,

...to gently peel off, as of layers of an onion [Oregon_Nurse]

‘Getting to the narrative’ and ‘hearing the story’ were identified as ways of getting to know, especially as typical patients requesting physician assisted suicide were described as people with a ‘story to tell’, for example,

I had an 82-year-old woman who was a survivor of World War II, a German woman. When World War II broke out, she and her then perhaps 8-9 year old daughter were taken to a war camp because her husband was English and her husband had left Germany because his life was at risk, so they were in a war camp during the entire war, this was in Dresden. They never, I mean, the horrors that they went through there we did not explore in detail, but there was a bond between this mother and child that was unbelievable, so at the end of the war, after the firebombing in Dresden and after the end of the war, the two of them went to England to look for her father and her husband. He, assuming that they had been killed, because he knew where the camp was in Dresden, had remarried and had another family, so once again there’s this incredible bond between mother and child. The mother had a brother who was on the staff at Portland State University so she came to the United States and worked here and created a life, and really was a member of the community, and she had been an activist in the Assisted Suicide Movement long before it became a law even. She had metastatic gastric cancer and was dying and her daughter came from out of town to come back to live with her during her terminal illness, and the two of them, two very strong German women went into the physician’s office to ask for physician-assisted suicide soon after the law was passed [Oregon_Nurse]

Getting to the narrative was thought to be important in assessment of capacity, with objectification of information thought to be less helpful and desirable by all but the psychiatrist,

Now the psychologist, I thought, did a more deeper, empathic evaluation of the patient’s state of mind, sense of self, sense of autonomy, sense of what death meant to that person, and it was a very beautiful narrative. The psychiatrists were more talking about, ‘I would code it this and I would code it that, and code it that.’ [Oregon_Nurse]

The interviewees identified the use of ‘gut feeling’ when making mental capacity decisions, based on a sense of knowing the patient; however a decision between relying on gut feeling and using a more structured assessment was highlighted by the physician, with gut feeling identified as the most frequently used mode of determining capacity,

Do I feel that this person’s decision is rational based upon what I know or can find out about their basic values, or is this something that’s very distinctly out of the ordinary, out of the character of this person?’ and looking at whether or not there’s any coercive issues from family or otherwise. Again, this is more of a gut feeling rather than having a check box, you know, we’d like to have a check box, but I personally don’t have that. [Oregon_Physician]

A position which was echoed by the lawyer,

After sort of asking all of those questions and assessing them mentally in our mind, yeah, we then reach the point where we say, 'Yes, this person meets that criteria.' But there's no checklist [Oregon_Lawyer]

The psychiatrist expressed some concern that this approach might result in a lack of objectivity, leaving the clinician open to missing valuable information especially about depression,

So it's not that everybody needs to go to a psychiatrist; they need to use some kind of screening that has a fair degree of sensitivity and specificity for depression in that context. It needs to be systematic, because I think that without systematic screening people go from their gut too much, and that's wrong [Oregon_Psychiatrist]

5.5.1.3.5.2 Accumulated experiential knowing

In addition to a sense of knowing the individual, the findings showed that there was a sense of accumulated experiential knowledge about the 'typical' capacitous patient requesting assisted suicide. This knowledge was based on a range of factors including personal experience of assessing patients requesting physician assisted suicide, talking with colleagues, reading the DWDA annual reports, familiarity with the research literature, and familiarity with the cultural and political landscape. This accumulated knowledge appeared to provide the individuals with a more direct route to knowing whether a patient had capacity or should have their capacity doubted.

This sense of accumulated experiential knowing was manifested in the interviewees' identification of the profile of a 'typical' Oregonian requesting assisted suicide, and this 'typical' description was talked about almost as a proxy for competence. The typical person was described as white, married, highly educated, not conspicuously religious and financially well off; in personality they are a 'planner' who has always been self-sufficient and independent. A need for control is an enduring trait and is likely to have manifested in the way they have conducted their lives,

...they've been independent all their life and they sort of ran their life. Nobody ran their life for them. And they have a sense of their own autonomy that trumps quantity of life, or quality of life, and they're very specific about their observant ego, their sense of self. And definitely not subservient, or not... they're more Alphas than they are Betas. [Oregon_Nurse]

According to one interviewee (the psychiatrist), they perhaps grew up in an 'alcoholic' household or similar circumstance which required them to be self-reliant at an early age. In adulthood they are 'rugged individualists' to whom independence and control are guiding values.

...most of them are...people who want to control, they are controlling people and they're people for whom that has been an enduring value, the need to control. (Oregon_Physician)

What the family say is that they have had this need to be in control, never be dependent on other people, captain of their own boat, lifelong, and it is both what has made them larger than life and attractive in some ways, and a pain in the butt in others. So it's been this lifelong characteristic and nobody is tremendously surprised then when they request assisted suicide. [Oregon_Psychiatrist]

They typically present themselves requesting assisted suicide at a non-advanced stage in their illness when they remain 'vigorous',

So they're pretty vigorous dying people. They're not shrivelled up in a bed and vulnerable. [Oregon_Nurse]

Another indicator of capacious decision making identified by the interviewees was the stated motivation for making the request. The interviewees thought that requests were rarely made due to current suffering but were usually motivated by a need to control the future, a fear of 'demeaning dependency' or a fear of future suffering. These were thought to be acceptable reasons for requesting assisted suicide,

When the patient says, 'I don't want to be a burden,' what they're saying is, 'I don't want to lose my autonomy.'...I know what it is – it's that independence...It is so important and with men more so than women. Women are used to being caregivers and they can adjust to being taken care of. Men cannot. Men absolutely refuse to have their bodily functions taken care of by somebody else. They hate it [Oregon_Lawyer]

There was an opinion among the interviewees that the majority of patients requesting physician assisted suicide share a personality profile with their assessing physician, therefore their reasons for wanting assisted suicide are likely to be found 'reasonable' resulting in their capacity not being called into doubt.

The doctor out there, Doctor xxxx, the one at the end there on the photograph, long hair, hippy, doesn't care for the standard suit and tie, and he has a lot of patients. He's typical of the doctors that participate. And I think that because they see that in themselves, they see this person come to them with... they say, 'I'm not going to deny that person.' It would be, in effect, denying themselves that right
[Oregon_Lawyer]

The findings showed that those who did not fit the usual profile or whose requests were motivated by reasons outside of the acceptable range were identified as 'outliers' whose capacity would be called into doubt and should therefore be evaluated in more detail. 'Red flags' included, being 'too quiet', 'too angry', 'too demanding', exhibiting 'hyper-religiosity' or being seen as attempting to manipulate the clinician,

But the other thing is, too demanding, almost manipulative or, 'I expect you, doctor, I expect you to do this because I'm entitled,' entitled demander, that can be just an axis 2 personality disorder, and you can try to overlook that, but if they're really putting on a show, then we need somebody else to take a second look.
[Oregon_Nurse]

Other concerns in a person requesting physician assisted suicide were high physical symptom burden, voicing financial worries, and a history of previous suicide attempts,

Okay, other outliers that would indicate it, 'I hate the government. I just hate it. I just want to get out of it. Money is always... they just want money, money, money. I just want to get out of this. I just want to get out of it.'...Whenever an outlier like that comes across in the intake, we always caution the doctors [Oregon_Lawyer]

All of the interviewees stated that they thought the vast majority of Oregonians they had seen requesting assisted suicide clearly had the mental capacity to make the decision to do so, and most of those that did not have capacity were easy to identify and screen out of the process. The patients arousing most concern were those in the 'grey' area who all thought represented a tiny minority of those requesting assisted suicide. Those identified as being in this grey area were thought to be difficult to assess because of the possibility that they were 'hiding' their

mental disorder or cognitive impairment; although one interviewee (the psychiatrist) thought that the ability to conceal such psychopathology could itself be evidence that the patient had sufficient capacity to negotiate the process.

Apart from facilitating easy identification of those with and without capacity, another perceived effect of this experiential knowing was that psychiatric assessment no was longer needed routinely and could be limited to the few patients in the 'grey area' because there was now an accumulated knowledge of what the psychiatric opinion would likely be for the majority of patients,

Then I would say, however, those doctors who get involved in the beginning should have psychological evaluations recommended, like we did in the beginning, so they can understand what the psychological community is saying. The psychiatric community is going to say, 'This is what I did and this is what I did.'...My recommendation would be that, in the beginning, because once the medical community then has a better understanding and is better educated, they're not going to need as many. (Oregon_Lawyer)

5.5.1.3.5.3 Knowing and community

In addition to a sense of knowing the typical Oregonian requesting assisted suicide, there was also evidence of a differential sense of knowing the patient between clinicians in the 'urban' and 'rural' communities in Oregon, which potentially impacted upon how they were assessed when requesting assisted suicide.

The findings suggested that those living in more isolated rural communities were more likely to make the request to their own general practitioner and go through the process locally than those in more urban communities who might go through Compassion and Choices of Oregon, not based just on their geographical location, but also because of a different ethos,

...my belief...is that there's urban ethics and there's rural ethics, and in rural ethics, it's more pragmatic. Here in the West, we say, 'Just shoot me when I'm done.'...I can't see somebody from the rural community coming up to the big university, the Town and Gown and the Ivory Tower, how intimidating is that? It's double intimidating to then to have to be interviewed and go through the process. So the doctors that are out in the rural area...I think they just do it and send in the paperwork. But at least they'd know their patient better, more likely, more likely. [Oregon_Nurse]

The effect of participating in the process as a clinician on personal reputation and standing in the community was also highlighted as an issue with profound personal consequences, e.g.

I was labelled 'Doctor Death' on the website of the xxxxxx...So these are the things that can happen...and it shows how difficult these evaluations are...So this to me obviously stands out again seven or eight years later because people still use this case at national meetings, the Right to Life people do, as the reason that this law is abusive... [Oregon_Physician]

This risk of being identified in the process was cited as a reason for not using the same doctors too many times,

I think also physicians don't want to be ostracised among their peers – 'That's the one who will,' or, 'That's the one who won't'. [Oregon_Nurse]

5.5.1.3.5.4 Knowing too well

In general, the professionals interviewed did not know patients prior to assessing them for physician assisted suicide and based their background knowledge of the patient on reports given by the patient's own general practitioner or other doctors who had had more longstanding contact with the patient. The concept of knowing too well was however evident in the interviews and there appeared to be two facets to this: knowing the *patient* too well and knowing the *process* too well.

In getting to know the patient, the interviewees described the typical process of assessment as unstructured, with capacity determination based on the clinicians' judgement of the patients' narrative rather than on checklists. The perceived risk in this process was that it could result in rather subjective judgment of capacity that might result in important clinical information being missed, a diagnosis of depression in particular. Mitigation of this risk of subjective judgement was proposed by advocating of the use of depression screening tools, although the administration of such tools was perceived by some as burdensome and un-empathic, and in practice not used often.

A key potential risk identified in getting to know 'too well' was that this could potentially cause harm to the patient by damaging their carefully constructed emotional 'veneer' which might be the only thing allowing them to manage the process of requesting assisted suicide,

After all these people I've seen, why would I want to peel away and leave them sort of bereft. They could have good conversations, but they're still dying and they need to know how they can die well and they qualify so they can die more easily than most of us can, if that makes any sense. [Oregon_Nurse]

Knowing the process too well was highlighted as an issue particularly by the lawyer, who perceived a risk that he might take shortcuts in assessment based on his extensive experience,

...maybe overexposure gets you to somewhere like where I am – you can tell pretty quickly if this person qualifies or not. That's good and bad. It's good in the sense that you have a real experience and understanding. It could be bad because you might be pigeon holing people too rapidly. You might be, 'Oh, this is good, this is that, put that in...' and you may be allowing some people in and allowing some out that shouldn't be out, and some in that shouldn't be in. [Oregon_Lawyer]

Practical strategies were proposed to minimise the risk of bias when knowing the process too well, including attending regular training workshops and not inviting the same doctors too frequently to conduct assessments,

So it's difficult, and we do have some good ones, though, that do, and they're in the neutral camp and we feel very comfortable with them being in the neutral camp. But then again, what do you do over time if they have so many? Do they become biased in a sense? Because this one psychiatrist has a checklist now, a two pager, that she uses and she writes out the whole thing, an analysis of the patient, and I read her analysis and boy are they thorough, but she's being seeing a lot and maybe we should back off and get somebody new. [Oregon_Lawyer]

This issue was seen as difficult to negotiate however because of the scarcity of doctors willing to participate in assessments, and even greater difficulty finding doctors willing to write the prescription for lethal medication.

5.5.1.3.5.5 Barriers to knowing

Despite concerns about knowing the patient and the process too well potentially risking a less objective (and therefore less rigorous) assessment of the individual and getting to know patients too well potentially causing harm to them by over intrusion, knowing was thought to be important in the process, and not knowing patients requesting assisted suicide well enough was expressed as a regret. Here the nurse in the sample talks about the importance of knowing the patient,

It should be primarily important, but in actuality, it's not...In a perfect world, if we were satisfying our sense of priorities and our sense of appropriate, professional assessment, we would know this patient. We would have known them for some time. But we're getting them at such a far end that the knowing is hard to get to. That's sad [Oregon_Nurse]

The interviewees identified a number of barriers to knowing the patient, including the healthcare structure presenting difficulties with clinician availability and time, ideological difficulties of not wanting to impose upon dying patients, meeting the patient at a late stage in life, and patients' reports of finding the process of assessment, especially by a psychiatrist, intrusive and distasteful e.g.

What we found in the early stages was that so many of our patients really felt that this was an imposition, you know, 'I'm not crazy, this is my own volition, I have thought about this,' and so we did not require it [Oregon_Physician]

5.5.2 Summary

The findings from the interviews with professionals experienced in assessing terminally ill adults requesting physician assisted suicide showed that the legalisation of physician assisted suicide in Oregon came as a surprise initially and the early years of the implementation of the law involved a hasty construction of the clinical assessment procedures.

A range of attitudes toward involvement were demonstrated and these reflected in part the range of views on the practice of physician assisted suicide but also individuals' confidence in the ability of their assessments to serve as appropriate safeguards in the process.

All of the interviewees considered the assessment of mental capacity important, but concerns were expressed about the reliability of the assessment due to the impact of personal views and values upon the assessment process. Objectivity in capacity determination was identified as an important goal which might be compromised by personal ethics.

All of the interviewees expressed the belief that the great majority of patients requesting physician assisted suicide would have the capacity to do so and that those lacking capacity would generally be easy to identify. Only a very small minority of patients were thought to be more difficult to assess and these were thought to be the ones hiding their 'true' motivations

from the assessing clinician-for these patients a psychiatric or psychological assessment was thought by the non-psychiatrists to be appropriate in order to uncover these hidden motivations.

The view was expressed that stringency in capacity determination should reflect that the patient would die anyway as a result of their disease, and there was a tendency toward a standard of competence in the non-psychiatrists that might allow those who were suspected of just lacking capacity to be given 'the benefit of the doubt' and given access to physician assisted suicide.

Capacity was conceptualised along a spectrum from a tight 'cognitive' to a broader more holistic conceptualisation echoing that seen in the expert submissions to the Commission on Assisted Dying and the main study sample.

Knowing the patient as an individual was thought to be important in determination of capacity, either with the patient being previously known to the assessor, or by gathering information about the person prior to assessment from those clinicians to whom the patient is known.

In the context of assessment of terminally ill adults requesting physician assisted suicide, knowing the patients' 'enduring values' was cited as a key aspect of being 'known'. Getting to know the patient involved processes such as 'getting to the narrative' and 'hearing the story', with a belief that patients requesting assisted suicide generally had a 'story' that they wanted to tell and be heard.

As well as knowing the patient as an individual, the findings showed that there was a sense of accumulated knowing gained from ongoing participation in the process and this way of knowing helped the interviewees to identify those with capacity based on 'profile' of the typically capacitous patient, and those who might lack capacity based on 'red flags' or non typical presenting characteristics. There was also an opinion expressed that there are common personality traits and outlooks between the patients requesting assisted suicide and the doctors assessing these patients which also provided a shortcut to capacity determination-if

the doctor and patient shared common views then the patient would more likely be found capacitous.

This sense of accumulated knowing was also perceived to be an important factor in explaining why specialist psychiatric assessments have become much less frequent for patients requesting assisted suicide in Oregon-there was an opinion expressed that they are no longer needed.

The findings showed a tendency toward the use of 'gut feeling' in capacity assessment rather than a reliance on more structured assessment or checklist based methods. There was a tension identified though between conducting a more 'palatable' but more subjective assessment vs a less palatable but more 'objective' capacity assessment. An assessment based on knowledge of the typical population and the narrative of the individual patient was seen as a more pragmatic (and possibly kinder) approach to assessment, but there was also caution about over reliance on gut feeling leading to the risk of missing those patients lacking capacity especially those with undiagnosed depression.

The findings showed a contrast between the Oregon interviewees' perception of how they assessed capacity and how they thought the patients' local doctors might assess capacity. There was a comparison made between urban and rural 'ethics', with rural approaches being more pragmatic and less intellectualised, although the interviewees described their own approaches as mainly based in pragmatism and gut feeling.

Whilst knowing the patient was thought to be important, a number of barriers to knowing were identified. These included ideological barriers (that getting to know the patient might cause them harm) systemic barriers (that clinicians' time and availability was limited and this might impact on getting to know the patient) and patient generated barriers (the patient finding assessment by a psychiatrist in particular intimidating and insulting and therefore inhibiting their wish to be known).

As well as a concern about barriers to knowing impacting on the quality of assessment, the findings showed a concern about the impact of knowing 'too well'. Knowing too well was

identified as knowing the *process* too well, which might lead to 'pigeonholing' of patients with judgements made which were based too much on past experience and not enough on assessment of each individual. Strategies were offered to compensate for this including continuing education and not using the same doctors too often to do assessments. Knowing the individual too well was only identified as a difficulty by one interviewee who expressed concern that this might result in harm to the patient by leaving them 'bereft'.

Because of the interviewees' circumstances of not being the primary clinician to the majority of patients they assessed, they perceived not knowing 'well enough' to be more of a problem than knowing 'too well' when referring to individual assessments, with their concern about knowing too well mainly expressed in reference to their sense of accumulated experiential knowing.

5.6 House of Lords debate leading to second reading of the Assisted Dying Bill

2014

On 18th July 2014 Lord Falconer presented the (England and Wales) Assisted Dying Bill to the House of Lords for a second time and a debate took place to which 133 peers contributed (Hansard, 2014). The debate lasted over eight hours and concluded with a second reading with no votes in opposition to the Bill proceeding to Committee stage. Of the 133 peers who chose to speak, 50 made some reference to mental capacity assessment as a safeguard in the Bill.

Of these 50, 22 supported the Bill, 23 opposed and five did not state a clear position.

The majority of those who stated support for the Bill talked about capacity assessment as one example of how the Bill was adequately safeguarded as it did not apply to those without mental competence. Only one peer who spoke in support of the Bill expressed any misgiving about capacity assessment as an adequate safeguard, saying that there is a

...need to assess emotional state as well as intellectual competence [Lord Rees of Ludlow]

None of the peers who spoke in support of the Bill talked in more detail about the process of capacity assessment although two stated explicitly that they thought that capacity assessment should be carried out by doctors rather than the judiciary.

All of the five who referred to mental capacity and did not state a clear position on the Bill expressed concern about mental capacity as a safeguard, and three of the five called for a Code of Practice to be built into the Bill. One thought that the assessment of capacity by two doctors would not be a sufficient safeguard and another thought that determination of competence should be carried out by a magistrate not a doctor.

The 23 peers who mentioned mental capacity and stated their opposition to the Bill voiced a range of concerns about mental capacity determination as a safeguard in the assisted suicide assessment process. Some thought that assessment of mental capacity was insufficient as a safeguard against vulnerable people accessing assisted suicide, e.g.

The term 'mental capacity' fails to capture the growing guilt and collapse of self-worth that may lead people to come to the view that they should not continue to be a burden to others [Lord Howarth of Newport]

whilst others talked about the difficulties involved in mental capacity assessment including the difficulty in determining this with certainty and the challenge of accurately assessing mental state perhaps due to patients hiding their 'true' mental state in order to negotiate the process. One Peer, (whose speech concerned mental capacity in its entirety) expressed the view that presumption of capacity and a requirement to prove a lack of capacity as stated in the MCA was not sufficiently stringent a threshold for assisted suicide and the applicant should be required to demonstrate a higher level of capacity,

The Mental Capacity Act...specifies that you have to prove that a person lacks mental capacity, the assumption being that everybody has mental capacity unless proven otherwise. For a decision as serious as assisted dying, doctors need to be certain that the person has mental capacity-a much higher hurdle to jump [Viscount Colville of Culross]

Another area of concern for a number of Peers opposing the Bill was that capacity assessment is proposed as the responsibility of doctors rather than the judiciary. Some thought that it

would be difficult to access medical professionals to carry out these assessments due to the likely reluctance of doctors to get involved. Examples were given of other practices where Peers thought that doctors' involvement has led to unintended negative consequences (the Liverpool Care Pathway and the Abortion Act); and the opinion was expressed by one Peer that doctors may lack the skills or training to assess mental capacity,

The noble and learned Lord's Bill assumes that a doctor can readily assess a patient's mental state but most doctors have little or no training or skill in capacity assessment, as was a matter of considerable concern for the post legislative scrutiny committee for the Mental Capacity Act, which I was a member of [Baroness Hollins]

This view was refuted by more than one Peer who stated their support for assisted suicide however, e.g.

The fact of the matter is that the Mental Capacity Act and the Mental Health Act and a lot of other legislation regarding mental health patients are totally predicated on doctors' ability to assess capacity, and they do so every day of the week. Therefore let us have none of that [Baroness Murphy of Aldgate]

Several Peers who opposed the Bill expressed their concern about a lack of a built in Code of Practice and a lack of proposed criteria for a determination of mental competence within the Bill, resulting in a lack of clarity about how the safeguard would operate in practice,

I have deep reservations about the Bill as it stands. The safeguards seem very weak. Surely it is not enough to have only the promise of an unidentified Code of Practice to be issued by the Secretary of State [Lord Shipley]

Regarding the impact of depression on mental capacity, Peers talked about data from Oregon showing that there have been instances of patients completing assisted suicide with a diagnosis of depression, and the evidence for a high prevalence of depression in those with a desire for hastened death. One Peer recounted her own experience of depression and how she believed this impacted on her decision making in the context of severe pain, and that had physician assisted suicide been available to her at that time she might have taken the opportunity because of her vulnerability due to the suffering she was experiencing.

A number of the peers, both those who opposed the Bill and those who did not state a position talked about knowing the patient in the context of assessment of capacity. Several

thought that a sustained relationship with the patient was important for a good assessment of capacity, and that this relationship was unlikely to be sufficient to complete a good enough assessment of capacity within the modern NHS,

The idea that doctors will have the time, let alone the competence and space to deal with these very challenging matters properly seems fantasy to me. How will this work in practice in the present climate in the health service? [Lord Mawson]

Time and continuity of care were cited as prerequisites to knowing which were thought to be lacking especially in general practice.

You will almost certainly not find a doctor who knows the patient [Baroness Butler Sloss]

One peer expressed doubt that doctors would be able to determine the full cultural context of requests for assisted suicide especially in inner city multicultural settings,

This is all subtle stuff for all of us, often unspoken and a can of worms. What training do our doctors have to be able to demonstrate the wisdom of Solomon in our inner cities when we live in multicultural communities? When faced with a human circumstance like this they will simply see the world through a biomedical prism. They will be unsighted, I suggest, on nine tenths of the human picture that will affect the decision [Lord Mawson]

5.6.1.1 Summary

There appeared to be a prevailing opinion amongst Peers who supported the Bill that mental capacity assessment was an adequate safeguard, and with the exception of one, they did not suggest any amendment to the Bill regarding mental capacity. This opinion was in contrast to those who opposed the Bill who voiced concern about a number of aspects of mental capacity determination as a safeguard.

Knowing the patient was thought to be important in the capacity determination process by a number of the Peers although none who expressed support for the Bill discussed this. Doubt was expressed by those in opposition that doctors would know those requesting physician assisted suicide well enough within the modern NHS to be able to adequately assess capacity.

Several of those who opposed the Bill expressed doubt that capacity assessment should be carried out by doctors and advocated for the assessment process to be the responsibility of the judiciary.

5.7 Discussion

In this chapter I have presented data from a number of sources that provide a basis for situating the findings of the main study.

The range of views on the legalisation of physician assisted suicide and belief in rational suicide of the doctors participating in the main study corresponded broadly to the range of views identified in a UK survey of senior doctors attitudes to the legalisation of assisted suicide, and both studies showed a diversity of perceived influences on the doctors' current attitudes, both religious and non-religious. This range of views and influences are shown in the main study to inform the complex context in which doctors know their patients, which in turn impacts upon the way in which capacity is assessed.

A comparison between the findings of the main study, the study exploring the expert submissions to the Commission on Assisted Dying and the findings from the interviews in Oregon showed that mental capacity is not a unitary concept; in all of these studies it was conceptualised along a spectrum, between a tightly defined cognitive conceptualisation and a broader concept encompassing areas such as voluntariness, motivation and autonomy. Definitions of capacity were elusive in all three of these studies and when offered were diverse and individually interpreted.

The findings show that presumption of capacity is impacted upon by views on assisted suicide, with the doctors in the main study and the experts presenting to the Commission who were more in favour of assisted suicide endorsing presumption of capacity more than those who were in opposition (although those strongly in favour also advocated a high standard of competence). The findings from the Oregon interviews showed that accumulated experience appears to have resulted in the opinion that the vast majority of patients requesting assisted suicide will have capacity for the decision and this is only doubted if certain 'red flags' are

present or the patient does not fit the usual patient profile. This opinion appears to be supported by data from a survey of doctors in Oregon (Ganzini et al., 2000b) showing that of 155 requests for assisted suicide, 144 (93%) were found to be competent to make the request, 8 (5%) were uncertain and 3 (2%) were found not to be competent.

A comparison between the findings between the main study and those from analysis of the Oregon interviews show that a sense of knowing is thought to be important in the process of capacity determination and the sense of knowing impacts on the approach to assessment; however there were some important areas of divergence which reflect the contextual differences in legal status of physician assisted suicide and the circumstances of the individuals interviewed.

A key difference between the findings of the main study and the findings from the Oregon interviews appeared to be a shift from knowing as perceived to be primarily located in the relationship between the individual patient and clinician, to a way of knowing located in a sense of accumulated experiential knowledge which is then applied to the individual being assessed. This way of knowing appeared to lend itself to a more pragmatic, “gut feeling” based assessment process, with the use of a structured assessment process appearing to be unusual. This cumulative knowledge also appeared to inspire a sense of confidence and certainty in the assessment process, with the result that more specialist assessment of capacity was thought to be rarely needed.

Further comparison of the findings of the main study and from the Oregon interviews suggests that there may be a difference in how knowing is conceptualised in the context of capacity assessment for physician assisted suicide before and after legalisation of the practice. There are, however, a number of reasons why this may not accurately reflect what is likely to happen in England and Wales if physician assisted suicide is legalised. As described in section 5.5.1.1 there are differences in political and healthcare contexts between Oregon and England and Wales. The constraints of a managed healthcare system as in the US will have produced its own pressures and moved the practice of physician assisted suicide in an administrative

direction that at present cannot be predicted within the NHS. Oregon is also very different from England and Wales demographically, geographically and socially. It is difficult again to predict how the 'Oregon system' of physician assisted suicide would translate to the England and Wales population with its greater size and density of population, multiculturalism, predominantly urban and suburban living and different cultural and political values. The non-psychiatrists in the main study all worked in local practice and anticipated assessing their own patients when they requested physician assisted suicide and, in the case of the psychiatrists, anticipated being referred patients by local GPs or physicians. Their ways of knowing the patient reflected these local as well as wider contexts. The Oregon interviews were with individuals who provide services accepting referrals from local clinicians who may not wish to involve themselves in the process or who are seeking a second opinion. I was not able to interview local Oregonian clinicians who had assessed their own patients requesting physician assisted suicide. A wider study involving interviews with local Oregon doctors who had participated in the process would provide a useful and more direct point of comparison with the findings of my study as the contextual factors would be more aligned. A qualitative survey of the experiences of Oregon doctors who have received requests for physician assisted suicide under the DWDA found that knowing the patient was a factor perceived to make assessment easier (Dobscha SK et al., 2004) although an earlier survey by the same authors found that nearly a third of doctors receiving a request for assisted suicide had known the patient for less than a month at the time of the assessment (Ganzini et al., 2000b).

It is not possible to know if, in England and Wales, assessment of patients requesting assisted suicide would be based mainly at a local level or whether a central referral system would emerge, perhaps through organisations such as Dignity in Dying. What appears possible, based on the comparison between my findings from England and Wales and Oregon, is that the sense of knowing and approach to assessment may differ depending on whether the patient is assessed by a local doctor or doctors, or through a more centralised assessment process.

In common with the findings from the main study, several Peers presenting to the House of Lords identified knowing the patient as an important factor in a good quality assessment of capacity although this view was only raised by those in opposition to the Bill in the context that the optimal level of knowing would not be achievable in our current health system. Whether those in favour considered knowing the patient important in capacity assessment was not possible to determine from the available data. Peers in favour of the Bill appeared to be reassured that the conceptualisation of capacity according to the Mental Capacity Act in the Bill was an adequate safeguard.

It is difficult to know whether the way doctors think they will assess capacity prior to legislation being passed is the way they will actually assess capacity if physician assisted suicide becomes legal in England and Wales. Also, the Oregon law gives no specific guidance on how capacity should be assessed and there is no mental capacity legislation to follow. In England and Wales, the guidance may be different, and may influence how capacity is assessed and documented, leading to a different relationship between the sense of knowing the patient and the way capacity is assessed.

Views varied within all of the studies about whether psychiatric assessment would be useful or desirable. In the main study the non-psychiatrists appeared to value the potential input of the psychiatrist especially in order to provide 'objectivity' in capacity assessment. In the expert submissions to the Commission on Assisted Dying views ranged from strongly supporting psychiatric assessment in all cases to finding this suggestion insulting and paternalistic. Again, within these submissions was an idea of psychiatric assessment as more 'objective'. In the Oregon interviews, psychiatric assessment was thought to be the province of the 'outliers', those that did not fit the pattern, the ones who might be hiding their true motivations. In all of the studies the disjunction between the non-psychiatrists' and psychiatrists' views of their abilities to provide 'objectivity' and divine these hidden motivations was striking, with the psychiatrists themselves not sharing the view that they possessed such skills. They viewed their expertise in a more limited way-to be able to diagnose mental disorder, but not

necessarily to be more able than their medical colleagues to determine when this would impair capacity or have a more objective view.

6 Situating Emerging Concepts in the Extant Literature on Knowing and Decision Making in Healthcare Contexts

6.1 Introduction

As described in more detail in section 3.6.2, in Grounded Theory methodology, the literature review provides a means of situating emergent theory within current thinking in related areas and 'can provide cues for raising its theoretical level and indicate which conversations to enter' (Bryant, 2007a).

A literature review was performed after the concept of 'contextualised knowing' emerged from the main study but insights gained from the literature presented in this review have informed and developed my theoretical understanding of the concepts emerging from my study. These insights have provided a broader theoretical landscape in which to situate my findings, and allowed me to identify where these make new contributions to what is known about 'knowing the patient' within the healthcare setting.

In considering the concept of 'knowing the patient' I will explore how this is conceptualised and described by different disciplines, focusing particularly on the medicine and nursing literatures.

In the main study, getting to know a patient in order to develop a sense of knowing was found to comprise three interlinked elements-temporality (the importance of time in knowing), dimensionality (seeing the bigger picture) and quality (hitting it off).

Knowing was highly contextual in my study, with a complex web of factors in both the doctor and patient influencing how a patient is 'known'. A sense of knowing was perceived to be important, but was also considered to be associated with risks, particularly in the loss of valued objectivity.

Within the literature on the clinician-patient relationship in healthcare there are various conceptualisations of the nature of this knowing relationship and its relevance to the goals of

care and identity of the healthcare discipline. That the relationship should be central to the clinical encounter however is a view common between the healthcare disciplines.

Within the nursing literature, 'knowing' is a concept placed at the heart of nursing philosophy and knowing the patient is viewed by some authors as the unique element that nursing brings to patient care. I will argue, with reference to the literature, that knowing the patient is also a key concept in medicine and there is less separating the ways in which doctors and nurses know their patients than might be suggested.

In my study, the way patients were known and the relationship between knowing the patient and decision making was found to be differently conceptualised for the sample interviewed in Oregon than in England and Wales. 'Gut feeling' was a term used by both samples however to describe an intuitive way of making decisions about capacity. This gut feeling was based on different ways of knowing in the samples though. In the England and Wales sample this was prospectively based on a sense of knowing the individual and in the Oregon sample this was based on cumulative sense of knowing the 'typical' applicant and the application of this typical pattern to the person being assessed. In contrast to the England and Wales sample who talked about using structured assessment approaches when a patient was not 'known', the sample in Oregon based their assessments almost exclusively on clinical intuition based on 'normal' pattern recognition, although the psychiatrist in the sample did present a critical view of this approach and advocated a more structured assessment. In this review I will show that 'gut feeling' or tacit knowledge is recognised within the healthcare literature as a prominent modality of decision making, especially for 'expert' decision makers and contrasts with more 'analytical' models.

In the following sections I will discuss my findings in relation to three areas: knowing the patient, ways of knowing in expert practice and the concepts of objectivity and subjectivity in clinical decision making.

6.2 Knowing the patient

Within the healthcare literature there is a considerable body of research addressing aspects of 'knowing the patient', both as a line of enquiry and as a research finding, and how this dimension of knowing impacts upon the clinical encounter. In this section I will explore the nursing and medical literature on knowing the patient, the contextual factors that influence the sense of knowing, and the relevance of knowing the patient to clinical experience and practice.

The table in Appendix 11 provides a summary of the studies concerned with knowing the patient in medical and nursing contexts which will be referred to in this section. As shown in the table, the majority of publications concerned with knowing the patient are in the nursing context; though more recently the concept of knowing the patient in medical contexts has received more attention.

In my study, the phenomenon of 'knowing the patient' was situated within the context of a doctor-patient relationship in which the determination of mental capacity was the focus. The doctors in my main sample experientially and hypothetically based their assessment of mental capacity upon detailed conversation with the patient, a process of 'getting to know', and consideration of other relevant information in order to facilitate decision making. The sense of how the patient was known was identified as a central factor in the approach to decision making.

Many of the empirical studies that have been influential in developing the model of knowing in nursing practice have taken place in a setting where the patient is not able to engage in verbal communication e.g. in a critical care setting or with neonates e.g. (Swanson, 1991, Jenny and Logan, 1992, Tanner et al., 1993, Crocker and Scholes, 2009, Henneman et al., 2010, Kelley et al., 2013), with fewer studies exploring the concept of knowing in circumstances where the patient was more cognitively able and conversant e.g. general medical and oncology settings (Henderson, 1997, Luker et al., 2000, Speed and Luker, 2004, Lotzkar and Bottorff, 2001, Macdonald, 2007). In medicine, only two empirical studies concerning knowing the patient

were found, both situated in a general practice setting (Fairhurst and May, 2001, Desjarlais-deKlerk and Wallace, 2013).

One explanation for the apparent dearth of studies concerning knowing the patient in medicine may be a difference in terminology. Evidence concerning knowing the patient in medicine may be 'hidden' behind the rhetoric of the 'doctor-patient relationship' or 'doctor-patient communication' which have a rich literature base e.g. (Ong et al., 1995, Szasz and Hollender, 1956, Dorr Goold and Lipkin, 1999, Emanuel and Emanuel, 1992, Halpern, 2003, Ridd et al., 2009, Balint, 1955, Bromberg, 1991) and places the intersubjective relationship between doctor and patient centrally in medical practice. There is also a growing literature focusing on narrative knowing in medicine, which emphasises the intersubjective elements of the doctor patient relationship by the interpretation of the patient narrative e.g. (Charon, 2001c, Charon, 2001b, Charon, 2001a, Launer, 2014, Launer, 2012, Launer, 2003, Launer, 1999, Launer, 2009, Greenhalgh, 1999, Greenhalgh and Hurwitz, 1999, Guglani, 2014, Hunter, 1996, Stanley and Hurst, 2011) and describes a particular way of 'knowing'.

This may not be the only reason why there is a more visible literature on knowing the patient in nursing practice. It may be that there is a rhetorical drive in nursing to defend the subjective elements of nursing practice in the face of the perceived threat of the devaluation of these elements. There appears to have been an evolution in how nursing practice is conceptualised on a background of the changing nature of the environment in which healthcare is situated. From Carper's initial focus on the caring relationship between nurse and patient (Carper, 1978), nursing epistemology has broadened to encompass the wider context of the organisation and society in which caring is situated (White, 1995, Allen, 2014). This broadening of scope has not been without criticism though. The literature on knowing the patient in nursing practice is orientated toward protecting the knowing relationship valued as central (and for some authors unique) to the profession of nursing e.g. Bonis (Bonis, 2009). There is a strong sense of a perceived threat to this valued element by the development of a healthcare system that is seen to promote efficiency and outcomes over the primacy of caring e.g.

(Whittemore, 2000), which has been reflected in a change in how nurses perceive that patients are known to them (Speed and Luker, 2004).

In comparing in more detail the medical and nursing literatures on knowing the patient though, there are more similarities in the findings than differences. As MacDonald points out in her review of technology and its effect on knowing the patient, 'knowing' often emerges as a theme in qualitative research with health care professionals even when is not initially directed toward the concept of knowing (Macdonald, 2008), an observation that has certainly been the case in my research. Knowing has been identified in a number of studies as an important element in the relationship between clinician and patient, the quality of which may influence healthcare outcomes.

The core elements of knowing the patient are very similar in studies within medicine and nursing: time, personal involvement and authentic engagement within the situational context appear to be common themes. The dual processes of 'knowing about the patient' and 'knowing the patient as a person' are again common to a number of studies across nursing and medicine.

Depending upon the context and setting in which studies were conducted, and the aims of the study, authors have reached different conclusions about the relevance of their findings. In the identified studies (all of which focus on situations of patient care), knowing has proposed implications in two key domains 1) for the clinician experience of care and 2) for patient outcomes. In the domain of clinician experience, a sense of knowing the patient provides a sense of authentic engagement and fulfilment of core values (Fairhurst and May, 2001, Charon, 2001b, Swanson, 1991), enhances the perception of the provision of good quality care (Luker et al., 2000, Crocker and Scholes, 2009) and enhances the sense of a therapeutic relationship (Lotzkar and Bottorff, 2001). In the domain of outcomes it has been proposed that knowing the patient enhances clinical judgment and expert decision making (Benner and Wrubel J., 1989, Jenny and Logan, 1992, Tanner et al., 1993), improves patient participation in care (Henderson, 1997), contributes to patient safety (Henneman et al., 2010), enhances

individualised care (Kelley et al., 2013), provides a basis for the selection of individualised interventions (Radwin, 1995a, Radwin, 1995b) reduces the risk of 'difficult encounters' (Macdonald, 2007) and may impact on health outcomes (Desjarlais-deKlerk and Wallace, 2013).

When considering these studies in light of my findings, the key domains of knowing are similar. Time, knowing the patient as a person, and a sense of engaging the authentic self in the interaction all resonate strongly with the experience of the doctors I interviewed. That knowing is central to the clinician's ability to make decisions also resonates with my findings. What is less evident in the published literature on knowing the patient is a critical evaluation of the impact of knowing on the approach to decision making. In the nursing literature in particular there is a prevailing sense that knowing the patient is positive and enhances 'good' clinical decision making, without then examining what that might comprise. Only two of the reviewed studies put forward the possibility that knowing the patient might have potential negative implications for decision making, by inviting assumptions about the patient on behalf of the clinician (Desjarlais-deKlerk and Wallace, 2013) or eroding the quality of clinical decision making due to an overly empathic response to the patient (Jenny and Logan, 1992).

6.3 The relationship between knowing the patient and clinical decision making

The interface between knowing the patient and clinical decision making in nursing has been explored in most depth by Radwin in a grounded theory study of nursing practice on a cardiology unit (Radwin, 1995b). Through participant observation and in depth interviews with 'expert decision makers' she developed a process model for knowing and decision making within nursing practice. The core process comprised 'two related components', the first being the nurses' 'understanding of the knowledge of the patient' and the second being the provision of 'individualised interventions'. The strategies for selecting these interventions varied according to familiarity with the patient, which in turn was impacted upon by the time spent with that patient. Four strategies were identified: 1) Empathising, 2) Matching a pattern, 3) Developing a bigger picture and 4) Balancing preferences with difficulties. Empathising and

matching a pattern were identified in 'low familiarity' situations whereas developing a bigger picture and balancing preferences with difficulties were identified in higher familiarity situations.

Empathising (described as the nurse imagining what her feelings might be if she were in the patient's situation) was used as a proxy to familiarity and guide for decision making when the patient was not known. Matching a pattern referred to the 'pattern or configuration comprising the experiences, behaviors (sic), feelings, and/or perceptions of previously cared for patients in similar situations. The nurse matches that knowledge about the patient being cared for within that pattern'. Developing the bigger picture relied on 'extensive knowledge of the patient' and was informed by knowledge of the patient's life and preferences outside of the hospital setting, with interventions selected to match the needs and values of the patient in their wider context. Lastly, balancing preferences with difficulties occurred when the nurse was able to ascertain the patient's wishes and preferences and balance these against a) her personal discomfort with the decision and b) the risk of ill effects of that preference for the patient. In addition to the identification of knowing strategies, 'not knowing' was identified as part of Radwin's negative case analysis, which was described by a nurse participant as 'I just thought I did my job' when she cared for a man whose 'experiences, behaviors, feelings and/or perceptions were not known'.

This study demonstrates some parallels with my findings in terms of examining the effect on decision making of how well a patient is known, showing the use of different decision making strategies according to the knowing condition. Radwin's study appears to show that a greater knowledge of the patient results in more willingness to take risks on their behalf if this is felt to benefit patient care, a view echoed by Whittemore (Whittemore, 2000). This study also appears to show a greater engagement of the self in decision making when the patient is better known vs not known, a dimension that also resonates with my study.

The findings of my study advance these findings in a number of ways. Firstly I have shown in the study of doctors in England and Wales that in the situation of mental capacity assessment,

perceptions of how well a patient is known might influence the choice of decision making framework used, with gut feeling being preferred where a patient is known, but more structured approaches being favoured if a patient is not known or known 'too well'. There is little exploration in the extant literature of the meaning of 'knowing too well' and the impact of this perception upon decision making. That there is a perceived 'optimum' level of knowing that facilitates 'good' decision making beyond which this is at risk, has so far been underexplored in the literature.

Another area that has been underexplored is the impact of the individual clinician perspective on the type and quality of decision making in healthcare contexts. My findings showed a complex set of individual and professional factors that influenced the approach to assessment and decision making. There has been little focus on this area in published studies, with a tendency in the nursing literature in particular to describe disciplinary rather than individual approaches to decision making. This may reflect, however, the homogeneity of the samples in the individual studies which contrasted with my heterogeneous sample of doctors where individual approaches and differences were perhaps more evident.

Another finding of my study was how important an influence community setting was on how the patient is known and the effect that involvement in assisted suicide assessments might have upon the clinician involved, with rural clinicians having a much stronger sense of the potential impact upon them and their professional and social communities.

There has been little examination in the literature on the effect of community on knowing in the clinician patient relationship. Only two studies were identified that have selected their samples to account for changes in geographical location (Desjarlais-deKlerk and Wallace, 2013, Luker et al., 2000), and only one of those specifically addressed how the type of community might impact on the clinician patient relationship (Desjarlais-deKlerk and Wallace, 2013).

In the course of my review of the literature on knowing the patient, I found that none of the studies mapped comfortably in circumstance or scope onto the situation I have explored in my study. Assessment of mental capacity to request physician assisted suicide is very different, for

example, from ventilator weaning or critical care. It is not therapeutic in the sense that the published studies are situated in therapeutic environments. Despite these differences though there appeared to be common elements in the development of a sense of knowing that were recognised by the doctors in my main study which adds further credibility to my findings and detail and range to the models of knowing described in previous studies.

6.4 Ways of knowing in expert clinical practice

One of the most striking findings in my study was the difference in decision making approaches between the England and Wales and the Oregon samples. The Oregon clinicians, who were working within an environment where physician assisted suicide has been legal for nearly two decades were more comfortable with, and reliant upon a 'gut feeling' approach to capacity decision making than were the England and Wales sample. One hypothesised explanation for this difference is that the Oregon clinicians are able to use tacit knowledge, based on cumulated expertise in assessing these patients, on which to base their decision making. The term 'tacit knowledge' to describe the implicit mode of knowing that contributes to 'expert clinical judgement' was first introduced by Polanyi (Polanyi, 1967) and has also been described as 'intuitive knowledge' (Gadamer, 1975). Tacit knowledge, according to Polanyi, cannot easily be described or defined. It is 'know how' that is 'pre-linguistic' and can only be developed through practice and non-formal learning. In healthcare, tacit knowledge allows clinicians to know how to act in *particular* situations, where there is a 'logical gap' between the available evidence and the solution (Henry, 2006), and expert practice is exemplified by the ability to traverse this gap.

The gathering of and ability to fluidly utilise tacit knowledge are proposed as the key conditions for expert practice, and models of the personal development of expertise are described. In nursing, for example, Benner (Benner, 1982) developed a model of development from 'novice' to 'expert' in nursing practice. According to this model, a nurse moves from being a novice with an initial reliance on rules to guide practice, through advanced beginner status to competent and proficient practice based on growing experience, finally reaching

expert practice defined by the ability to make 'graded qualitative distinctions', develop 'common meanings', be able to anticipate particular courses of events, use paradigm cases and personal knowledge of similar situations, utilise 'cryptic maxims' (idiosyncratic sayings or truisms that are applied to the clinical situation) and engage in practices that are gained through experience, not through specific training.

Following from their earlier model, from the findings of a qualitative study of how expert nurses use intuitive judgement, Benner and Tanner (Benner and Tanner, 1987) developed a 'typology of knowing' comprising pattern recognition, similarity recognition, commonsense understanding, skilled know how, sense of salience and deliberative rationality. They found that 'proficient and expert performers' have developed a 'deep web of perspectives that causes them to view a situation in terms of past situations' resulting in a kind of selective attention which 'permits fluent performance'. In Benner and Tanner's study, a note of caution was raised about the development of 'a wrong set of perspectives' leading to 'the human error of tunnel vision'. The authors talk here about the way that experts use strategies to prevent this error; for example using detachment, objectivity and rational calculation, the negative effect of which can be that expert performance deteriorates to mere competence or even novice like levels. The alternative strategy of 'deliberative rationality' is proposed as a way to 'clarify one's perspective by considering how one's interpretation of a situation would change if one's perspective were changed' a task which involves stepping back and considering other approaches.

It is possible that the difference in approaches between my two samples engages with these models of the acquisition of expertise and that there are two kinds of 'expert knowledge' demonstrated in my study. The first (as demonstrated in the England and Wales interviews) may be *expert knowledge of the individual patient* which might lead to a decision based on tacit knowledge and modes of reasoning if the patient is known well. It may also be that in the case of the England and Wales sample (and echoed by the transplant clinicians), that the deliberate move toward more structured decision making when a patient is known 'too well'

engages with a sense of risk of the ‘human error of tunnel vision’ described by Benner and Tanner, resulting in the use of the strategies they describe to limit this potential error. The second may be *expert knowledge of the patient group* (as demonstrated in the Oregon interviews), leading to decisions based on tacit knowledge independent of how ‘well’ the individual is known or even despite the patient not being ‘known’ at all.

Empirically, my study is the first I am aware of that has been able to clearly draw out this distinction, and certainly the only study that looks at these issues in relation to mental capacity assessment in a medical context.

6.5 Objectivity/subjectivity within clinical decision making

The findings of my study showed that objectivity in decision making was valued by the doctors and a threat to this sense of objectivity by knowing ‘too well’ prompted a conceptual move toward more structured approach to decision making. This phenomenon was echoed in the interviews with the transplant clinicians.

A recent discourse on the relative values of objectivity and subjectivity in clinical practice interfaces with the concerns expressed by the clinicians I interviewed. In their recent editorial exploring the place of subjectivity in psychiatric practice, Yakeley and colleagues (Yakeley et al., 2014) present a critique of ‘the dominance of positivism’ within modern psychiatric practice and argue that this has led at least in part to the widespread criticism of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorder: DSM V (American Psychiatric Association, 2013) and the declining popularity of psychiatry as a career of choice. They argue that subjectivity is considered a ‘limitation or hindrance to the accuracy and effectiveness of the task in hand’. They define subjectivity as ‘the individual’s experiences, feelings, beliefs and desires, prejudiced and partisan’ in contrast to objectivity as ‘a stance free from the vagaries of human perception, personal interpretation, past experiences and preconceived expectations’, the very factors that are held, particularly within the nursing literature, to be central to knowing the patient. The authors are critical of psychiatry’s attempts to codify and classify expressions of subjective experience into objective nosological

systems and the marginalisation of more subjective approaches e.g. psychoanalysis. They identify the inherent tension between the ideals of creating a relationship between doctor and patient: the 'person centred approach' (a central focus in medical student education) and the ideal of objectivity in medicine. They make the observation that the forging of the doctor-patient relationship as taught in medical school is not conceptualised as an intersubjective and inherently emotional process, but as a series of behavioural techniques to facilitate information gathering within the consultation and 'powerful emotions that arise within both the patient and doctor may remain unspoken, minimised or completely denied'. The authors ultimately advocate for a need to 'subjectify the objective in order to heal unhelpful splits in our epistemological thinking' and promote 'affective subjectivity' with reintegration of the subjective perspective and 'self-reflective personal development' into psychiatric clinical practice.

This position resonates strongly with the findings of my study. Several of the doctors talked about their perception of objective decision making as a fallacy but felt that objectivity was expected of them as clinicians and decision makers. It may be that their discomfort with their ability to remain objective when making a decision about mental capacity is an acknowledgement of these unspoken emotions. The findings of my study engage with this discourse and challenge the presumption of medical objectivity in mental capacity assessment.

6.6 Summary and discussion

Knowing the patient is a concept that is recognised and valued in healthcare, and particularly in nursing. Within a caring context 'knowing the patient' may lead to a range of outcomes for both clinician and patient. Within the literature on assessment of mental capacity, the concept of knowing the patient has neither been explored nor emerged as an outcome though it has been raised as an area of concern in the recent House of Lords' debates on the Assisted Dying Bill. The findings of my study resonate strongly with what is already known about the core elements of knowing the patient and take the concept further than previously by demonstrating the interrelationship between knowing the patient, expert practice and the

perceived value of objectivity in clinical decision making and the change in these relationships and impact on decision making approach with time. My findings and literature review have also led me to question the assertion that knowing the patient is unique to nursing practice- both the doctors in my studies and doctors interviewed in other qualitative studies examining doctor patient relationships have described knowing the patient as a core element in medical practice. This sense of knowing has essentially the same core elements as those described in nursing practice. Depending on the focus of the study, the sense of knowing the patient was linked to various outcomes, but there was no clear distinction between those described in nursing, compared with medical studies. Knowing was linked in most studies to better patient care and better clinician experience. That knowing the patient too well might be associated with risks associated with poorer decision making has only been touched upon in previous studies but was a central concern for the doctors in my study that drove the approach to decision making. Further exploration of this finding in other settings might provide a valuable insight into the way clinicians make decisions especially when the decision is ethically or personally challenging.

In my study, a rich and complex interplay of personal factors informed the way in which patients were known. Previous studies examining this concept have focused more on the core elements and processes of knowing than the contextual factors that influence the approach to getting to know and the concept of 'contextualised knowing' provides a new dimension to the concept of knowing the patient.

7 Discussion

When a person requests physician assisted suicide in a jurisdiction where it is legal, the main tasks of the assessing clinician are to 1) to determine the conditions under which that request can be met e.g. does the patient have a physical illness from which they are likely to die within the next six months and if the patient fulfils this condition, 2) to determine whether the patient has the mental capacity to make the decision to end their life.

The task of mental capacity assessment for terminally ill adults requesting physician assisted suicide is neither clinically diagnostic nor therapeutic, although in formulating the decision diagnostic elements are relevant e.g. does the patient have a mental disorder or cognitive impairment impairing decision making capacity? The complex process of capacity assessment concludes with a binary decision as to whether the patient is mentally competent to end their own life by ingesting lethal medication.

In this thesis I have examined in detail, using qualitative methods, the assessment of mental capacity for terminally ill adults requesting physician assisted suicide. Taking a main sample of doctors currently practising in England and Wales I have carried out and analysed in depth interviews using a grounded theory approach. The findings from the main study, their comparison with the findings from analysis of other sources of data and a review of the pertinent research literature have resulted in the development of a theoretical model explaining the relationship between knowing and decision making in the substantive area taking account of contextual factors and time.

In this chapter I will firstly present a summary of the key findings from this study and some reflections upon the research process. I will then address the standards of rigour met by the study and present strengths and limitations. Next I will discuss the implications of the study findings for practice and policy both for physician assisted suicide and also medical practice more widely and show how findings of this project have contributed to the assisted dying debate to date. In light of these implications , I will make specific recommendations for consideration by those drafting new legislation, codes of practice and subsequent monitoring

of that practice. Lastly I will discuss future research directions suggested by the findings of this study.

7.1 Overall summary of research findings

The findings of this study show that for a theoretically sampled group of doctors in England and Wales, *knowing the patient* was a core condition of the process of assessment of capacity both generally and for the decision to request physician assisted suicide.

In the specific situation of assessment of capacity for physician assisted suicide, knowing the patient was found to be a contextual phenomenon impacted upon by a number of elements including the doctors' perspectives on legalisation of assisted suicide, their frame of reference (professional, personal or moral), their views on the meaning of suffering and the dying process and their conceptualisation of mental capacity (particularly cognitive vs broad, and whether their conceptualisation was in accordance with the principles of the Mental Capacity Act 2005).

Knowing and the process of getting to know were individually interpreted and depended on both the doctor and patient individually and also the intersubjective relationship between them. The process of getting to know comprised three elements: temporality, dimensionality and quality leading to a *sense of knowing*. A role for both doctor and patient was foreseen in the process of getting to know, particularly in the domain of quality.

Contextualised knowing, the sense of knowing informed by the factors presented above was found to be on a spectrum from *not knowing* to *knowing too well*. The place of the doctor patient relationship on this spectrum related to the way assessment might be approached and this variation was based upon preservation of *valued objectivity* whereby the achievement of a sense of an objective assessment process was valued above the subjective judgement based on the doctor patient relationship. To preserve valued objectivity the approach to assessment varied according to how well the patient was known. If a patient was not known or not known well, a structured procedural approach was favoured; for patients who were *known* there was a tendency toward a gut feeling based approach; but when a patient was known *too well* there

was a perceived threat to valued objectivity and a return to a procedural, structured approach was favoured in order to return the sense of objectivity to the assessment process.

The model described above 'fit' in the context of the England and Wales sample (prior to legalisation of physician assisted suicide) but when considered in light of a context in which physician assisted suicide has been legalised for some years (the Oregon experience), variation in the conditions and contextual factors impacted upon the model. When taking into account the sense of knowing shifting from a relationship conceptualised according to each individual encounter toward a cumulative sense of knowing based on a growing body of similar encounters and decisions, decision making appeared to be based more consistently on gut feeling rather than structured procedures.

It is postulated that if physician assisted suicide were legalised, over time the approach to assessment of capacity would lean more toward a gut feeling based process, especially if a small number of experienced clinicians were responsible for the majority of assessments.

On exploring the literature on knowing and decision making, the model that emerged from analysis of the empirical data showed several parallels with what is already known in this area including the importance of authenticity in the clinical encounter and finding the narrative. In particular there is resonance with Benner's theory of expert knowledge in which time and experience (either of the patient or situation) leads clinicians to use implicit reasoning processes based on the acquisition of tacit knowledge. Deliberative rationality as described by Benner and Tanner (Benner and Tanner, 1987) may be akin to the process used by doctors to return to a more explicit mode of reasoning once the patient or situation is known 'too well'.

7.2 Reflections on the research process

In accordance with Strauss and Corbin's condition of 'self awareness' as a quality indicator in grounded theory methodology, the following sections present some reflections upon using a grounded theory approach, the reflexive stance and on the writing up process.

7.2.1 Reflections on using a grounded theory approach

This study used qualitative methodology primarily with a grounded theory approach, although thematic analysis and framework analysis were used in related studies that informed the theoretical sensitivity to and interpretation of the main findings.

Prior to beginning my PhD studies I had not used qualitative methodology before as the majority of the research I done previously had used epidemiological methods. I had always been interested in using qualitative approaches though and was keen to use my PhD studies to achieve a grounding in qualitative methodologies.

Grounded Theory is a methodology which requires discipline and attention to detail. My experience with learning the theoretical basis and procedures of grounded theory methodology have shown me that good quality qualitative research is a rigorous process which requires patience as well as tenacity.

Expertise in the use of grounded theory methodology will need time to develop. At the outset of this study I found it challenging to envisage how exactly the process would culminate in the development of a set of credible findings. Having gone through the process now from beginning to end I look forward to developing further studies with a greater understanding of and confidence in the methodological approach and my own ability to apply this approach to the research problem.

7.2.2 Reflections on reflexivity

As a clinician who is both a psychiatrist and has experience of working with people at the end of life, I found parallels between myself and many of the doctors in my sample. Like some of the participants I assess capacity and use the Mental Capacity Act on most days of my clinical working life. Like a number of my participants I have grappled and sometimes struggled with the theoretical and clinical challenges of balancing my duty to protect patients with my duty to empower them. During the process of this study I have, like some of my participants, become increasingly aware of the personal value base I bring to my clinical work.

I have also during the process of exploring the relational nature of mental capacity assessment become less certain of my own capacity decision making and more inclined to see the frameworks I use as constructs that are only as good at their job as I am.

One area where I was particularly aware of the influence of my specialist training on the analysis was in the interpretation of the non-psychiatrists' ideas about what special skills the psychiatrist possesses. Had I not been trained as a psychiatrist I might not have interpreted the perspectives of some of the non-psychiatrists in the main sample in the same way. I might have seen the skills of the psychiatrist only through their eyes, sharing the view that psychiatrists are better able to judge hidden motivation and have greater powers of objectivity than other clinicians. My interpretation (shared with the psychiatrists in the sample) of this perspective as essentially flawed may not be shared by all of my fellow psychiatrists, but reflecting on my own practice of capacity assessment leads me to doubt this faith. The process of conducting this study has contributed to my consideration of myself as culture and value bound as every other doctor, and my decisions as contextualised as they were for the doctors in my study.

7.2.3 Reflections on the writing process

I found that the process of writing up facilitated and supported the use of the constant comparative method. As writing up progressed I was better able to see how the findings of my study compared and contrasted with those of other studies I had conducted and with the literature on knowing the patient and clinical decision making. These comparisons helped me to refine my conclusions by critically analysing my data in comparison to other work. The process led me to ask further questions of my data for example the findings of my study exploring expert submissions to the Commission on Assisted Dying led me to make direct comparisons with my interviews and look more carefully at presumption of capacity and support for the Mental Capacity Act.

7.3 Evaluation of methodological rigour

In section 3.4 I outlined the procedures by which I aimed to demonstrate theoretical and analytical rigour. In this section I will reflect upon the success of this study in meeting those criteria. According to Charmaz,

As we evaluate where we have been and what we have gained, we look back on our journey and forward to imagining how our endpoint appears to our readers...The endpoint that we portray makes sense to us because we have been immersed in the research process, for our readers however the lines become blurred between process and product.

In this study I set out to use methodological processes that were consistent with a grounded theory approach and aimed to employ these processes in order to produce *credible* findings. A transparent philosophical framework underpinned the study and a reflexive stance was employed. Among the procedures used in this study were the explicit use of sensitising concepts, theoretical sampling, use of the constant comparative method, a systematic coding strategy, using the participants' words in coding, negative case analysis and seeking respondent and stakeholder validation of the emergent findings.

That 'knowing the patient' is a concept present in discussion of mental capacity for physician assisted suicide in other unrelated contexts i.e. the Oregon interviews and the House of Lords debate on assisted suicide lends credibility to its relevance as a concept in the substantive area.

With my 'insider' perspective as a practicing psychiatrist, the findings of the study whilst unanticipated at the outset have clinical resonance for me. For the participants who chose to give their reflections on the findings they thought the findings made made 'sense' indicating that for those participants the findings are credible.

7.4 Strengths

This qualitative study of assessment of capacity for patients requesting assisted suicide is the first study of its kind, and provides an insight into the perspectives of doctors practicing in England and Wales as well as a comparison with another medical and social culture in which assisted suicide is practised legally.

The study makes an original contribution to the understanding of this area by using qualitative rather than quantitative methods for exploring the perspectives of those doctors to whom the ramifications of this part of the Assisted Dying Bill will be most relevant. The methodology used allows the research to move beyond hypothesis testing and surveying attitudes and into the development of new theory in an area which has not been ethically or clinically resolved to a point where legislators and medical practitioners can be confident that mental capacity testing provides an adequate safeguard. This methodology has enabled more in-depth analysis of reasoning frameworks in mental capacity assessment and therefore examines process as well as outcome.

It is aimed that the conclusions of this study will inform further debate at a Parliamentary level as the Assisted Dying Bill continues its course through the House of Lords and potentially through to Parliamentary debate.

7.5 Limitations

The main limitation of this study is the circumstance in which the interviews took place. Because the doctors in England and Wales were discussing their hypothetical response to a request for assessment of capacity for a patient requesting physician assisted suicide it is uncertain whether the emergent model fully reflects the approach that would actually be taken within the situation. The findings of this study though will provide a useful point of comparison for further planned studies investigating mental capacity assessment for physician assisted suicide. Within grounded theory methodology, emergent theory is considered to be a 'work in progress' which is modifiable as new data and insights become available. It has already been shown that the emergent model from the main study was modified under different contextual conditions, and further modification may be necessary if physician assisted suicide is legalised in England and Wales.

7.6 Implications of the study findings

Consideration of the issue of the assessment of capacity to request physician assisted suicide for the terminally ill spans clinical, legal and ethical domains. In the following sections I will

discuss the implications of my findings both in relation to the ongoing assisted dying debate and in terms of their contribution to the extant literature on knowing the patient in healthcare contexts.

7.6.1 Assessment of mental capacity for assisted suicide

If physician assisted suicide is legalised in England and Wales, doctors participating in assessment of mental capacity will at first be relying on their knowledge and experience of mental capacity assessment in general in conjunction with what knowledge they have of the person they are assessing. The 'expertise' described in the published literature on 'knowing' also describes knowing through experience of similar situations in the same contextual setting. The findings from analysis of the Oregon interviews suggest that in routine clinical practice, assessment of patients requesting assisted suicide is uncommon and that local doctors are not exposed to multiple assessments that would allow them to build up a high level of experiential knowing and training is fairly 'light touch' to reflect this. Instead, assessments of capacity are done mainly by clinicians based at or nominated by 'Compassion and Choices of Oregon' where most of the patients are not 'known' personally to the clinician prior to assessment. The findings of my study reflect the conclusions of a number of the studies exploring knowing in clinical practice that decision making based on 'knowing the patient' whilst valued in nursing practice was distrusted to an extent within my sample of doctors especially when the sense of knowing reached beyond a comfortable personal threshold. There was also a tension between the ways in which the doctors in my study said they would actually make their decision (using a 'gut feeling' approach) and how they thought it was expected for them to make the decision (using 'objective' approaches).

If legalisation proceeds according to the current iteration of the Assisted Dying Bill, doctors would be required to adhere to the legal framework of the Mental Capacity Act 2005.

According to the findings of my study, capacity decisions based on 'knowing the patient' are largely implicit, so when the outcomes of assessments built on a foundation of knowing are translated into the framework of the Mental Capacity Act they may not accurately reflect the

cognitive and emotional processes the doctor has gone through to arrive at their conclusion. With each decision, a wealth of past experience, personal attitudes and other contextual factors will individualise the decision but possibly not in the way envisaged by the legislation. The Bill and those that publically support the Bill argue that capacity assessment will be straightforward for the majority of patients and if there is any doubt a psychiatrist can be consulted and in the case of ongoing doubt assisted suicide should not proceed. This set of steps however assumes that the initial assessment of capacity is appropriate and accurate and will use a reasonable (and fairly consistent) threshold for doubt and that patients will be referred appropriately for a second opinion. The low psychiatry referral rates in Oregon and other countries where physician assisted suicide is legalised would suggest one of two things- either capacity is very clearly either present or absent in the vast majority of people requesting assisted suicide or that doctors completing initial assessments rarely see a need for such a referral when perhaps such a need exists.

According to the annual reports from Oregon in the first five years of the DWDA, referrals for psychiatric evaluation were relatively frequent but after five years dropped dramatically and have remained low ever since as shown in Table 1.

The reasons for this are unclear but it is possible that this reflects the development of institutional sense of 'knowing'. Frequently described is the 'typical' Oregonian who wishes to end their life by assisted suicide-quintessentially a white, well educated person who values their personal autonomy above all. This demographic is reflected in the figures from the annual reports where around 97% of people ingesting the medication are white and around 45% are highly educated (baccalaureate or higher) (Public Health Oregon, 2013).

It may be that this stereotypical pattern recognition provides a 'short cut' to knowing the patient and informs the assessment of capacity. This proposition is supported by the findings from analysis of the interviews in Oregon in which the study participants described a sense of feeling more comfortable with their assessments of patients who conformed to the expected demographic stereotype. It has been argued in support of the safeguards in the Oregon

legislation that there are 'no vulnerable groups' given that there is no evidence that women, ethnic minorities and the financially disadvantaged are over represented (Battin et al., 2007). This is countered however by the argument that the overrepresentation of the white, wealthy and well educated actually identifies *them* as the vulnerable group and that there may be factors within that group such as fear of loss of autonomy that make it more likely that they will seek physician assisted suicide and these fears may not be adequately addressed because of the acceptance of them as 'legitimate' reasons for assisted suicide (Finlay and George, 2011).

It may be that development of this cumulative 'knowledge' is inevitable, but is it desirable? In the main study, the doctors I interviewed valued objectivity as the hallmark of a 'good assessment' whilst acknowledging 'knowing' as a cornerstone of their relationship with their patients. However, does a 'good' assessment of capacity necessarily need to meet the ideals of 'objectivity?' or could a capacity determination based on thoughtful intersubjectivity be considered 'good enough'? Will society acknowledge and accept a process which is inherently interpersonal and that over time will be informed by the collective knowledge of the 'typical' applicant? If this is the standard to which society aspires then it may be that a capacity assessment nominally based on the framework of the Mental Capacity Act but necessarily variable in ways which cannot be predicted, accounted for or standardised is sufficient as a safeguard. However, so much is written on both sides of the debate about the need for 'watertight' safeguards, certainty and 'checks' that the inherent intersubjectivity of the process may not be seen as 'good enough'. The findings of my study show that using the vocabulary of the Mental Capacity Act does not guarantee that its premises and processes will be followed and these findings are echoed in the findings of the study examining the expert submissions to the Commission on Assisted Dying and the conclusions of Mental Capacity Act post legislative scrutiny committee.

A truly 'objective' assessment of capacity based on measurable and repeatable elements might risk being merely a test of retention of information, a criticism that is not new. To arrive at the

type of nuanced, thorough assessment of capacity envisaged by the Commission on Assisted Dying it is hard to see how intersubjective variability can be avoided, if in fact it should be. If those developing the legislation wish doctors to engage in capacity assessment in a meaningful way they must risk inconsistency and a loosening of the safeguard, yet if they wish for all patients to receive a comparable assessment irrespective of the clinician performing it then the 'test' will necessarily be diminished in complexity and likely permit all but the significantly cognitively impaired, severely depressed and frankly delusional to proceed.

The findings from analysis of the interviews in Oregon suggest that there has been some engagement with this problem but no satisfactory solution. The compromise there appears to be the tendency to 'not go there' regarding the more emotionally difficult intersubjective elements of the assessment, purportedly to protect the patient from further suffering but possibly to protect the clinician from the perceived risks of their own emotional engagement and subjective stance.

7.6.2 The impact of values on the assessment of capacity for assisted suicide

The response to suffering and the meaning of a wish for death at the end of life emerged as important contextual factors for the doctors in my main study and the impact personal value bases have been a key area of exploration in this thesis.

Hamilton and Hamilton (Hamilton and Hamilton, 2005) explore the 'competing paradigms' of assessment of a patient wishing to end their lives and compare the traditional model where the response to suicidal thoughts would be a thorough psychiatric assessment and an attempt to prevent the suicide taking place if possible, with the 'assisted suicide competency model' where a psychiatric assessment infrequently takes place. The authors illustrate this with a detailed case description in which a terminally ill patient is admitted to a psychiatric hospital with worsening paranoia. A search of his home results in the removal of firearms and ammunition, but the medications he has been given under the Oregon Death with Dignity Act for his planned suicide are left untouched. The authors argue that these paradigms are

fundamentally incompatible and present inconsistencies which do not properly serve the needs of the patient.

Parker (Parker, 2013) though, is critical of psychiatrists' prevailing position in opposition to physician assisted suicide, suggesting that this position is based upon hidden faith based values prohibiting physician assisted suicide transposed into secular arguments resting on the links between mental disorder and suicidality, risk of coercion, and the difficulties of providing a robust assessment of capacity. He argues strongly for an ethical lack of distinction between killing and withdrawing/withholding life sustaining treatment saying that this is rooted in religious ideas about the ethical difference between human vs non-human agency in death. He cautions that the assessment of capacity and rationality 'can be subject to the risk of being driven by preformed values'. He further criticises the assignment or 'discovery' of 'phenomena' passed off as diagnosable 'mental disorder' as presenting a potential barrier to progression through the process of physician assisted suicide. He is particularly critical of this in comparison with assessments for withholding active treatment where these phenomena may not be similarly ascribed. He takes the position that 'values and positions are not authenticated, but glossed over in the language of clinical necessity'. His criticism, however, appears to be limited to those whose clinical decisions do not fall in favour of allowing physician assisted suicide. He does not propose an alternative solution to determination of mental capacity except to compel clinicians to 'come clean' about their value base. This presupposes that clinicians are wholly cognisant of these values, which this thesis would argue is not always the case. Whilst religious doctors may be clear in their own minds about the moral permissibility of killing, there are a plethora of often subtle and unconscious influences that are brought to bear on clinicians' decisions which may have just as much influence on the situation as religious beliefs (Varghese and Kelly, 2001, Miles, 1994, Maltzberger and Buie, 1974, Hughes, 2000). Also, I would argue that an ethical view in favour of physician assisted suicide is no less value based than one of opposition.

I agree with Parker that the inherent value ladenness of capacity determination renders it risky, but I would argue that this weakness undermines the legislative effort, given that capacity determination is held as central to proposed legislation.

7.6.3 Knowing the patient in healthcare contexts

In addition to examining in detail the concept of knowing in the context of capacity for assisted suicide, a more general consideration of knowing in healthcare contexts formed a significant part of this thesis.

One of the main conclusions reached in comparing the nursing and medical literature on knowing the patient was that the difference in the ways patients are known by these different disciplines may be more rhetorical than actual. There were several parallels in how patients were known between the two literatures although in the medical literature the phenomenon is significantly underexplored, perhaps because culturally 'knowing' is seen as less fundamental to practice.

Also, the findings of my study extend what is known about knowing and decision making by considering how approaches to decision making might vary according to how well a patient is known and how knowing 'too well' impacts on how decision making is approached. Of particular interest in this regard was the resonance of this model for non-medical practitioners working in a liver transplant setting showing that the model may be translatable to other clinical situations.

7.7 Research impact

As a result of my involvement in research into mental capacity for physician assisted suicide I have been fortunate to have had a number of opportunities to discuss and disseminate my developing knowledge and research findings and use these findings to inform the ongoing debate on the legalisation of assisted suicide. In section 7.8 I will make specific recommendations related to mental capacity in three key areas, based on the findings of this study. The contribution, along with Prof Matthew Hotopf, that I was able to make to the evidence gathered by the Commission on Assisted Dying was considered in the report

published by DEMOS (DEMOS, 2012); a paper I co-authored with Prof Hotopf and Dr William Lee presented an argument for why psychiatrists should engage with the assisted dying debate and has been cited over 40 times (Hotopf et al., 2011b). In December 2013 I contributed to a well attended seminar for Peers in the House of Lords discussing the issue of mental capacity for assisted suicide and also been interviewed on the radio (BBC Radio Cambridgeshire) on this subject.

As a member of the Royal College of Psychiatrists Parliamentary Liaison Committee I have been able to use my knowledge to contribute to the College response to the developing legal situations in England, Wales and Scotland and contributed to a College position statement prior to the Second Reading debate in the House of Lords in July 2014.

More recently I co-authored a 'President's blog' with Prof Sir Simon Wessely, the President of the Royal College of Psychiatrists (RCPsych) discussing the role of the College in the assisted dying debate (Wessely and Price, 2014) and have presented to the RCPsych Council in order to inform their discussions on the College position on assisted suicide.

I have presented my developing findings at the Royal College of Psychiatrists Faculty of Liaison Psychiatry Annual Conference on two occasions (2013 and 2014).

The paper I co-authored on concepts of mental capacity for assisted suicide (Price et al., 2014) has been accessed over 4000 times since publication in April 2014.¹⁹

On 7th November 2014, the House of Lords convened at Committee Stage to debate tabled amendments to the Assisted Dying Bill. A number of the proposed amendments related to mental capacity determination as a safeguard, particularly relating to the standard of capacity required. Differences of opinion were expressed about the standard required ranging from a stringent standard of 'commensurate capacity' also described as 'supercapacity' to that required under the Mental Capacity Act 2005.

In the course of debate, Lord Alton of Liverpool remarked,

¹⁹ See Appendix 12: Published papers (3)

I was not surprised by the remarks of the noble Baroness, Lady Hollins, with all her experience as a former president of the Royal College of Psychiatry. I was not surprised to hear what she had to say, but I was particularly struck by a report published in April of this year by Price, McCormack, Wiseman and Hotopf. (Parliamentary Debates (Hansard), 2014)

He went on to quote from (Price et al., 2014) as part of his speech expressing concern about mental capacity as a safeguard in the Bill. No votes were cast on whether to accept any of the proposed capacity amendments on that day, but Lord Falconer expressed his intention to further consider the capacity provisions in the Bill in light of the preceding debate.

7.8 Recommendations

In the UK in 2015, the assisted dying debate is still firmly on the public agenda, within a wider context of a broader professional and public debate on the expectations of modern medicine in an environment in which people are living longer with long term, life limiting conditions within a financially straightened healthcare system.

There is a developing discourse on the balance between quality and quantity of life for people with life limiting illness e.g. (Gawande A, 2014, Granger K, 2015) and social media such as Twitter and Facebook facilitate public contribution to the debate. In 2014 for example, the death by physician assisted suicide in Oregon of Brittany Maynard, a young woman with cancer (Associated Press, 2014), prompted an international public and media (including social media) response to her decision with further calls to legalise assisted suicide in England and Wales.

Further attempts to change the law are highly likely and whilst recent debate in the House of Lords advanced the discussion on the place of mental capacity determination in the process of assessment for physician assisted suicide, much is still yet to be clarified. The most recent attempt to change the law stalled as there was insufficient time to complete the Committee stage before all proposed amendments could be debated. A key amendment agreed at the Committee stage debate, however, was that cases should be subject to judicial review. This amendment is likely to be incorporated into any further Bills presented to Parliament in England and Wales.

The findings of this study have informed recommendations regarding development of any further legislation to allow physician assisted suicide and are presented in the following sections.

7.8.1 Recommendation for a clearer definition of mental capacity and process of capacity assessment.

Approach to assessment of mental capacity for physician assisted suicide is likely to vary considerably between involved clinicians, with a resulting impact on the process and potentially the outcome. How mental capacity is conceptualised should be clear within any new Bill to legalise physician assisted suicide with detailed consideration of the proposed assessment framework, the process of assessment and expectations of capacity assessment and in any associated codes of practice.

7.8.2 Recommendations for the assessment structure and process for patients requesting assisted suicide

At present it is unclear in what setting assessments of adults requesting physician assisted suicide would take place should the practice be legalised. The findings of this study show that the assessment context may have a significant impact on the process. For this reason a clear statement of intent should be made on whether assessment of adults requesting physician assisted is seen as a core (but optional) NHS activity, a process for which assessing clinicians would receive a fee (as for e.g. Deprivation of Liberty Safeguards or Mental Health Act Assessments), a process that could be accessed centrally through organisations similar to Compassion and Choices of Oregon, or a combination of these.

Judicial review of the assessment process presents an opportunity to scrutinise each case and assess the mental capacity assessment process. Clinicians should be able to demonstrate the process of capacity assessment as well as the outcome. In order to do this, a recommendation to record each mental capacity assessment process should be carefully considered. This process could then be reviewed by the court, with expert peer review if necessary. In this way the mental capacity assessment process could be scrutinised in individual cases and a record of

all mental capacity assessments would be available for further analysis as part of an ongoing process of post legislative (and clinical) scrutiny.

7.8.3 Recommendations for reporting requirements should physician assisted suicide be legalised

Oregon requires that assessing clinicians report all cases of physician assisted suicide to a central body (Oregon Public Health Division), with data collated and reported annually. These collated data are often referred to as evidence that the process is properly safeguarded and that there is no 'slippery slope'. There are weaknesses in the dataset however, as only data from those who have been prescribed the lethal medication are collected and reported. The available reports do not give sufficient information to assess whether mental capacity determination is an adequate safeguard as they do not present any data on those who request assisted suicide but are not deemed eligible and for what reason(s).

To determine whether the proposed safeguards fulfil their purpose, data should be required to be returned for every patient requesting physician assisted suicide, with details of the assessment process and reasons for the outcome. Collated data can then be analysed to assess the effectiveness of the safeguarding process.

In addition to a requirement for assessing clinicians to return data on their assessments, they should also be required to report on the nature and length of their relationship with the patient; in what professional setting and context they are assessing the patient (including any financial remuneration) and whether they have any affiliation with organisations supporting physician assisted suicide. In this way, a more detailed picture of the context in which assessments are being carried out could be built and scrutinised.

7.9 Future directions

In undertaking this study I not only had an opportunity to explore in detail the initial research question, but also in response to the emergent findings to consider the relationship between knowing and decision making in different healthcare contexts. The findings of my study suggest future directions for research enquiry which are discussed in the following sections.

7.9.1 Mental capacity for the decision to request assisted suicide

In order to further verify the findings of this study in clinical practice, the next step might be to use qualitative methods to explore the doctor patient interaction as it happens. To my knowledge no such study has been conducted in a jurisdiction where physician assisted suicide is already legal. Using observational and interview based methods, the doctor and patient could be interviewed separately before and after capacity is assessed and the doctor patient interaction(s) could be observed in detail. In this way, the model that has been derived prospectively from this study could be tested, developed and refined. This methodological approach does have precedent: in an exploration of mental capacity assessment, Emmet et al (Emmett et al., 2013) conducted an ethnographic and interview based study of clinicians' assessment of capacity for hospital discharge decisions in older people with dementia.

7.9.2 Assessment of mental capacity in healthcare contexts

Jurisdictions with mental capacity legislation have rejected outcomes based and status based models of capacity in favour of a functional model whereby capacity decisions should be made based on the process of decision making alone (Wong et al., 1999a). There is some evidence from my study though that when faced with a decision that doctors see as extraordinary or perhaps as a proxy indicator that mental illness is present, they have a tendency to move toward a presumption of incapacity and from a functional toward an outcomes based or status based model. This issue has also been highlighted by the post legislative scrutiny committee for the Mental Capacity Act 2005.

Following the presentation of my findings at a conference in 2013, I received the following email from a delegate which indicated some resonance with clinicians in a wider sense suggesting that my findings may have applicability beyond the situation of assisted suicide,

I'm following up from the liaison faculty meeting a fortnight ago when I spoke to you briefly – please could I have a copy of the posters you presented on capacity and assisted suicide? I've been working with the geriatricians and orthopods on a recording capacity in the general hospital and though it is a very separate issue, the 'assumption of capacity' recognised by psychiatrists, that you point out is something that appears to stand out here as well.

Further research focusing on the principles and approaches used by non-psychiatrists in the assessment of mental capacity in other healthcare contexts could provide a valuable insight into the observed disjunction between the principles and procedures of Mental Capacity Act 2005 and clinical practice.

7.9.3 Knowing the patient in healthcare contexts

The main findings of this study and related review of the literature suggest further exploration of the concept of knowing particularly in the context of medical practice and in medical decision making as an intriguing line of enquiry. There appears to be a growing shift in the medical literature toward narrative and values based medicine where subjectivity is inherent. A potential strategy would be to further the findings of this study by exploring in other medical contexts the concept of knowing and how it relates to ideas of objectivity and approaches to decision making. Further exploration of the underexplored concept of 'knowing too well' could also potentially yield findings that make a contribution to what is already known about 'knowing the patient' in healthcare.

A study making an explicit comparison between doctors' and nurses' ways knowing and approaches to decision making would also provide a further source of knowledge about how the patient is known across disciplines in healthcare contexts.

Lastly, there is very little in the published literature addressing the impact of ways of knowing on patient outcomes. Studies addressing the relationship between knowing and healthcare outcomes could potentially make a valuable contribution to the healthcare literature.

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Appendix 1: Invitation letter to potential study participants

Dear

Assisted dying for the terminally ill is currently a subject of much interest and debate by professional bodies, the media and the public.

I am interested in exploring senior doctors' views on mental capacity assessment for those patients requesting assisted suicide and this forms the basis of my PhD project.

I am writing to invite you to participate in a one to one interview in which I will be asking your views and opinions about mental capacity assessment as it applies to this group of patients in your capacity as a doctor who may be asked to be involved in this process were it legal in this country.

The interview takes approximately one hour and can take place face to face or over the telephone depending on your preference and geographical location. The interview will be audio taped and transcribed with your consent. The interviews will be anonymised at the time of analysis so that your confidentiality will be ensured.

This project has ethical approval from The Joint South London and Maudsley and the Institute of Psychiatry NHS Research Ethics Committee. REC reference 06/Q0706/36

I would be very grateful if you could complete the enclosed form and return it to me in the pre-paid envelope provided, indicating your availability to participate.

If you would like to discuss the project with me prior to deciding or for any other reason, I can be contacted by email at a.price@iop.kcl.ac.uk or by telephone on 07970059522.

Many thanks for considering this request.

Yours Sincerely,

Dr Annabel Price

Clinical Research Worker and Honorary Specialist Registrar in Psychiatry
King's College London, Institute of Psychiatry.

Appendix 2: Information sheet for participants

Participant Information Sheet:

Research Project: Mental capacity assessment for terminally ill patients requesting physician assisted suicide: a qualitative study exploring the perspectives of medical professionals in England and Wales.

I would like to invite you to participate in a research project.

What is the purpose of the study?

I am interested in exploring senior doctors' views about mental capacity assessment as it applies to assisted dying legislation. The findings of the study will contribute research to inform the ongoing debate about the proposed legalisation of assisted suicide by providing further information about an important but under-researched aspect of the process. This project forms part of my PhD thesis and has ethical approval from the Joint South London and Maudsley and the Institute of Psychiatry NHS Research Ethics Committee REC reference 06/Q0706/36

What do I have to do?

I will be asking you to take part in a one to one interview which will take place either face to face or by telephone. The interview will be audiotaped and transcribed with your consent. I will also send a short form asking for some information about you. This will help me when analysing the data. Following the interview I will ask you permission to contact you again if there are any questions that arise after the interview has been transcribed. This is entirely voluntary and you are free to refuse.

Why have I been chosen?

I have already interviewed a participant in your area and have used a process of 'snowballing' which identifies potential participants close to the original participant. Your contact details are freely available on local databases of medical practitioners and your professional details were compatible with the inclusion criteria for my study.

Do I have to take part?

No. There is no requirement for you to take part. You may also stop taking part in the research at any point. You do not have to give any reason for not wanting to participate.

Are there any risks?

The research does not involve any investigations or treatments which might put you at risk.

Will the information I give stay confidential?

Yes. All information you give is confidential. The information you give may be used for a research report, but it will not be possible to identify you in any way from this.

If you have any questions please contact:

Dr Annabel Price
Clinical Lecturer
Department of Psychological Medicine
King's College London, Institute of Psychiatry
Weston Education Centre
10 Cutcombe Road
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SE5 5AW

020 7848 5157
07970059522

Annabel.Price@kcl.ac.uk

Appendix 3: Consent form for participants

CONSENT FORM

Title of Project: Mental capacity assessment for terminally ill patients requesting physician assisted suicide: a qualitative study exploring the perspectives of medical professionals in England and Wales.

Name of Chief Researcher: Dr Annabel Price

Annabel.Price@kcl.ac.uk

Please initial box

1	I confirm that I have read and understand the enclosed information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	<input type="checkbox"/>
3	I agree to take part in the above study.	<input type="checkbox"/>
4	I do not agree to take part in the study.	<input type="checkbox"/>

Name of Participant

Date

Signature

Appendix 4: Initial topic guide

Topic Guide: Mental capacity assessment for patients requesting assisted suicide

- ❖ Relevant details about the participant
 - Name (to be removed at analysis)
 - Age
 - Ethnicity
 - Specialty
 - Years as a consultant/GP
 - Current post and years in current post
 - Exposure to terminally ill patients
 - Any other information relevant to views on this subject
- ❖ Participant's views on assisted dying for the terminally ill
 - General views on assisted dying for the terminally ill
 - Familiarity with the Assisted Dying for the Terminally Ill Bill
 - General views on the Assisted Dying for the Terminally Ill Bill
 - Response to a patient requesting assisted suicide were it legal
 - Participation in the practice were it legal
 - Initial assessment of patients making requests
 - Mental capacity assessment
 - Prescribing medication
- ❖ Mental capacity assessment: general considerations
 - General understanding of mental capacity assessment
 - Mental capacity assessment as a safeguard for the vulnerable
 - Mental capacity assessment for patients requesting assisted suicide
- ❖ Mental capacity assessment for patients requesting assisted suicide
 - Initial assumptions
 - What is already assumed about a patient requesting assisted dying
 - Process of determining mental capacity
 - Information needed
 - Practical and time considerations
 - Content of patient assessment
 - Autonomy and rationality
 - Certainty
 - How to be certain that a patient does or does not have capacity and how this is known
 - Patients who lack capacity
 - Next steps and duties
- ❖ Professional roles in the capacity determination process
 - The assessing doctor's role
 - Recognising that mental capacity is in doubt
 - Knowing when to refer
 - Any thoughts/concerns about the assessing doctor's role
 - The psychiatrist's role
 - Should psychiatrists be involved in the determination of mental capacity for this group
 - Specific skills and expertise
 - Any thoughts/concerns about the psychiatrist's role
 - The referral process
 - Which patients

- Which circumstances
- When
- What for
- Any concerns about the process
- Training considerations
 - How to train competent assessors of capacity
 - How to ensure competence
 - Who to train
- Other professional groups
 - Are there other professional groups who could take on the capacity assessment role
- ❖ Ethical and personal issues
 - How do personal views affect professional decisions in general
 - How do personal views affect professional decisions in this situation
 - Can personal views be separated from the capacity determination process
 - Objectivity
 - Is this achievable
 - If so how to achieve it
 - Knowing the patient
 - Does having prior knowledge of the patient affect decision making
 - Rational suicide
 - Views on this concept
 - Do these views affect how mental capacity is conceptualised
 - Other relevant ethical/personal considerations
- ❖ Other relevant issues

**Appendix 5: Summary of the Assisted Dying Bill 2005 given to research
participants prior to interview**

Assisted Dying for the Terminally Ill Bill: Summary

Purpose of the Bill

This is a Bill to 'enable an adult who has capacity and who is suffering unbearably as a result of a terminal illness to receive medical assistance to die at his own considered and persistent request; and for connected purposes.

Authorisation

The Bill authorises a physician to assist a qualifying patient to die by prescribing medication, and if necessary prescribing and providing means for the patient to self administer that medication in order to end their own life.

Qualifying conditions

Two physicians must examine the patient: the attending physician and a consulting physician. The attending physician will have been informed by the patient in a written, signed request that they wish to be assisted to die. ***The physician will have examined the patient and their notes and be satisfied that the patient does not lack capacity*** and determined that the patient has a terminal illness and is suffering unbearably as a result of the illness.

The attending physician will also have:

- Informed the patient of their medical diagnosis, prognosis, the process of being assisted to die and alternatives to assisted dying including palliative care.
- Ensured that a palliative care specialist attends the patient
- Recommended that the patient notifies their next of kin of their wishes
- Satisfied themselves that the request is made voluntarily and that the patient has made an informed decision
- Referred the patient to a consulting physician

The consulting physician will have:

- Been informed of the patient's wish to die
- Satisfied themselves that the patient does not lack capacity
- Confirmed the diagnosis
- Concluded that the patient is suffering unbearably as a result of their illness
- Informed the patient of the alternatives
- Satisfied themselves that the request is made voluntarily and that the patient has made an informed decision
- Advised the patient that they will be required to make a declaration which they can revoke.

Determination of lack of capacity

If in the opinion of either the attending or consulting physician, the patient may lack capacity, the attending physician shall refer the patient to a consultant psychiatrist, or a psychologist, who will independently assess the patient's capacity

For the purposes of the Act, a person lacks capacity if they are unable to make a decision for themselves in relation to the matter because of 'an impairment of, or a disturbance in the functioning of, the mind or brain resulting from any disability or disorder of the mind or brain'.

Declaration

When the qualifying conditions have been met, the patient must make a declaration of their wish to die in a form prescribed by regulations made by the Secretary of State. The declaration must be witnessed by two individuals, one of whom should be a solicitor or public notary. Neither the attending or consulting physician, nor the psychiatrist or psychologist, nor a relative or partner of the patient may witness the declaration.

Duties of the assisting physician

The assisting physician can be either the attending or consulting physician.

- The assisting physician may not take any action to assist the patient to die until 14 days after they have provided their written wish to be assisted to die.
- Before taking steps to assist the patient, the assisting physician will have
 - Informed the patient of their right to revoke the request
 - Asked the patient to confirm that the declaration has been revoked

Conscientious objection

No person is under any obligation to participate in any diagnosis, treatment or other action authorised by the Act except to make patient records freely available to a new physician who does not conscientiously object if requested to do so.

No establishment is obliged to permit an assisted death on its premises

No person is obliged to raise the option of assisted suicide with a patient, to refer the patient to a source of information or to refer a patient for assistance to die.

Appendix 6: Final topic guide

Topic Guide: Mental capacity assessment for patients requesting assisted suicide
Introduction (to be read to participant)

In this interview I would like to explore your views about mental capacity assessment for patients requesting assisted suicide in your role as a medical professional who may be required to make such a determination should the Assisted Dying for the Terminally Ill Bill become law. The interview will be tape recorded and transcribed for analysis, but your personal details will remain confidential and the information will not be available to anybody not directly connected with this research project. I may also make some short notes during the interview with your permission.

This interview will last approximately one hour, but you are free to discontinue whenever you wish.

- Check that the interviewee is still willing to participate
- Check that this time and place is still convenient, and arrange an alternative time and place if not

- ❖ Relevant details about the participant
 - Specialty and professional role
 - Exposure to terminally ill patients
 - Familiarity with the Assisted Dying for the Terminally Ill Bill
 - Any other information relevant to views on this subject

- ❖ Mental capacity assessment: general considerations
 - General understanding of mental capacity assessment
 - Purpose
 - Process
 - Four step test
 - Examples of capacity assessments
 - Mental capacity assessment as a safeguard for the vulnerable
 - Mental capacity assessment for patients requesting assisted suicide

- ❖ Mental capacity assessment for patients requesting assisted suicide
 - Is it always necessary to formally assess a person's mental capacity in order to say they possess it in this circumstance?
 - Initial assumptions
 - What is already assumed about a patient requesting assisted dying
 - What kind of person might request assisted suicide?
 - Process of determining mental capacity
 - Information needed
 - Practical and time considerations
 - Content of patient assessment
 - Use of instruments, aids to determination of capacity
 - What would it mean to you to say that a patient possess the capacity to end their life?
 - Autonomy and rationality
 - Motivation
 - How might you go about ascertaining a patient's motivation for requesting assisted suicide?
 - How good are we at determining people's underlying motivations?
 - Coercion
 - Duress
 - Perceived duty or burden
 - Mental illness and cognitive impairment
 - Depression and capacity

- Advanced directives
- 'non-reasoned communication' in cognitive impairment
- Confidence/margin for error
 - How to be confident that a patient does or does not have capacity and how this is known
- Patients who lack capacity
 - Next steps and duties
- ❖ Professional roles in the capacity determination process
 - The assessing doctor's role
 - Recognising that mental capacity is in doubt
 - Knowing when to refer
 - Any thoughts/concerns about the assessing doctor's role
 - The psychiatrist's/psychologist's role
 - Should psychiatrists be involved in the determination of mental capacity for this group
 - What do you think would be expected of you? What might your responsibilities be in this context?
 - Specific skills and expertise
 - Any thoughts/concerns about the psychiatrist's role
 - The referral process
 - Which patients
 - Which circumstances
 - When
 - What for
 - Any concerns about the process
 - Training considerations
 - How to train competent assessors of capacity
 - How to ensure competence
 - Who to train
 - Other professional groups
 - Are there other professional groups who could take on the capacity assessment role
- ❖ Ethical and personal issues
 - How do personal views affect professional decisions in general
 - What drives decision making in general?
 - How do personal views affect professional decisions in this situation
 - Can personal views be separated from the capacity determination process
 - When might your role as a person supersede your role as a doctor?
 - Impact of decision making on the professional
 - Can you remember a capacity decision that left you feeling uneasy or in doubt?
 - How do you think being involved in this process might impact on you personally?
 - Impact of decision making on the patient
 - Objectivity
 - Is this achievable
 - If so how to achieve it
 - Knowing the patient
 - Does having prior knowledge of the patient affect decision making
 - What is knowing the patient?
 - Ways of knowing the patient
 - Impact of knowing on process and outcome
 - Rational suicide
 - Views on this concept
 - Do these views affect how mental capacity is conceptualised

- Other relevant ethical/personal considerations
- ❖ Participant's views on assisted dying for the terminally ill
 - General views on assisted dying for the terminally ill
 - General views on the Assisted Dying for the Terminally Ill Bill
 - Response to a patient requesting assisted suicide were it legal
 - Participation in the practice were it legal
 - Initial assessment of patients making requests
 - Mental capacity assessment
 - Prescribing medication
- ❖ Other relevant issues

Appendix 7: Open coding example

Excerpt from interview	Initial codes
<p>INT Do you think there is anything about somebody's general personality or outlook that might make them more likely to seek that means of ending their life?</p>	
<p>RES Yeah, I think a bit of a negative outlook on life, people who tend to look for solutions... it's difficult isn't it? Sometimes you see patients who seem to have a certain degree of fairly minor suffering and you see them running around not using medicines for their pain. Other people you see tend to get into a situation where they end up on as many painkillers as you could possibly imagine anybody being on for what is perhaps to your prejudice relatively minor suffering. I think that might be part of the character makeup of people who would feel that assisted suicide was the best way out once things got much worst still.</p>	<p>Pessimism, problem solving, outlook on life</p> <p>Personal interpretation of suffering</p> <p>Clinician's judgement about level of suffering</p> <p>Personality factors</p> <p>'ways out'</p>

Appendix 8: Emergence of categories example

Excerpt from interview	Initial codes	Categories
<p>INT Do you think there is anything about somebody's general personality or outlook that might make them more likely to seek that means of ending their life?</p> <p>RES Yeah, I think a bit of a negative outlook on life, people who tend to look for solutions... it's difficult isn't it? Sometimes you see patients who seem to have a certain degree of fairly minor suffering and you see them running around not using medicines for their pain. Other people you see tend to get into a situation where they end up on as many painkillers as you could possibly imagine anybody being on for what is perhaps to your prejudice relatively minor suffering. I think that might be part of the character makeup of people who would feel that assisted suicide was the best way out once things got much worst still.</p>	<p>Pessimism, problem solving, outlook on life</p> <p>Personal interpretation of suffering</p> <p>Clinician's judgement about level of suffering</p> <p>Personality factors</p> <p>'ways out'</p>	<p>Influences on decision making: patient factors and clinician factors</p>

Appendix 9: Emergence of the core category

Development of the core category: knowing the patient

15/08/2008 (supervision notes)

- Why are psychiatrists nominated as those best qualified to determine mental capacity? Is this a question of greater knowledge and skill or do psychiatrists have greater ethical knowledge.
- Knowledge of the person versus distance in decision making-is this a boundary issue?

23/2/2009 (supervision notes)

Guidelines vs tacit knowledge pros and cons....

Trusting other professionals to have sufficient knowledge

Hegemony of knowledge-knowledge hierarchy- science vs person

28/09/2009 Interview with Oregon_2 (memo)

This is an interesting passage which demonstrates an important point: The feelings of both doctor and patient about the assessment can set up resistances on either side which can impair open dialogue. It may be easier to say that the patient has capacity than to challenge the patient with more searching questions. This may reflect a power relationship which goes in the patient's favour or discomfort on the part of the assessor causing reluctance to probe further.

Possible Trees 20090909

IMPACT

On the patient

On the clinician

On workload

Implications of capacity determination

Making mistakes

INFRASTRUCTURE

Support

Supervision and scrutiny

Mental Health Act

Mental Capacity Act

Training

Tools and instruments

Systems in services

Legal aspects

PERSONAL CHARACTERISTICS

Of the patient

Personality factors

Rugged individualism

Control

Autonomy

Of the doctor

PERCEPTIONS

Public perceptions

Perception of need for assisted dying

DECISION MAKING

Weighing in the balance

Uncomfortable decisions

SAFEGUARDING

RELATIONSHIPS

Between professionals

Level of agreement

Joint assessment

Discussion between professionals

Doctor-patient
Knowing the patient
Empathy with patient and family
Doctor patient interaction
ROLES AND RESPONSIBILITIES
Of the Professional
Role definition
Advocacy
Checking understanding
Best interests
Of the assessing doctor
Of the psychiatrist
Necessity for psychiatric referral
Of the patient
Self administration
CULTURE
Competence as a social construct
ISSUES
Complex situations
Being a burden
INFLUENCES
Peer group influence
Media Influence
Social influence
Family influence
Professional influence?

23/06/2011 interview with Se Doc_1 (memo)

The idea that the community a patient lives in is important in terms of how capacity assessment is conceptualised-a patient who is able to live alone and anonymously may be harder to assess. The community/family/network around a patient

This face value opinion that someone seems to have capacity-what is this based on? To this doctor it means 'he spoke sense, he knows where he lives and he knows the conditions around himself'. This appears to refer to a global impression of cognitive capacity.

07/07/2011 13:26 (reflective log)

Initial coding done on paper (first time I have done this after discussion with xxx)

I found this helpful as I didn't get too bogged down in detail and was able to see links with other sources.

SE GP_2 is a male GP trained in the UK working in North London in an urban practice. Frequent contact with dying people. Atheist, pro assisted dying.

This participant has an interest in end of life issues and an interest/expertise in mental health issues.

In this interview there was quite a lot about the idea of knowing the patient and how that might impact upon approach to assessment

07/07/2011 (reflective log)

Knowing the patient can be positive: GPs consider it a key positive aspect of their practice and perhaps what makes them unique. Knowing the patient may provide useful shortcuts in the capacity determination process because it enables the assessor to know whether the patient's presentation is consistent with how they have always been. It allows for comparison and contrast. It also allows for rapport building which may make the assessment process easier. What is knowing though? Is it a few meetings, is it knowing the medical history, is it knowing the family?

Is knowing the patient always positive though? Some interviewees have expressed pitfalls of knowing the patient-collusion, not wanting to let them down, not seeing them through

objective eyes. These factors may all bias a capacity assessment rather than helping. Knowing the patient also seems to predispose the doctor to using 'gut feeling' in assessment. How the patient 'seems'.

This theme should be explored further and more questions asked about what is to know the patient and how this affects assessment. Could be quite a significant theme.

Is there a hierarchy of knowing? Do GPs feel they 'know' their patients better than other doctors? Do different individuals/ specialties have different criteria for what constitutes knowing? Do doctors 'know' their patients in different ways? How do these ways of knowing affect how they determine whether a patient has capacity?

11/08/2011 Interview with SE GP_2 (memo)

Doctor functions differently depending on their perception of how well they know the patient

11/08/2011 10:07 Formality (memo)

Formality of assessment process seems to be guided by how well the doctor knows the patient prior to assessment. Knowing the patient well seems to lead the doctor towards a less formal, more implicit process of assessment, not knowing the patient might lead the doctor to use more formal processes and guidance like the MCA or COP guidance.

11/08/2011 10:20 (reflective log)

At this point there are a few areas which seem to be important and worth pursuing in more detail

1. Presumption of capacity
2. Knowing the patient and how this affects the process of assessment
3. Narratives-language used to describe patients and how this might be related to the way capacity is assessed

30/08/2011 10:07 (reflective log)

Work ongoing on analysis. Now completing SE GP_3 but have also been through all the interviews on paper as I felt I was losing sight of the bigger picture in the data. This has been productive as the theme knowing the patient has emerged strongly and after discussing this in supervision this seems to be a main theme on which I can build my thesis. I have also sent our recruitment letters to my Wales sample.

I am wondering about the concept of judgement and the role of judgement and making decisions on an individual basis. This seems to be based on so many different variables and factors within the patient's history and presentation. Within any law there would need to be room for judgement on a case by case basis but how much room is enough and how much is too much?

**Appendix 10: Emergence of the model of the relationship between
knowing and decision making**

Emergence of the relationship between knowing and decision making

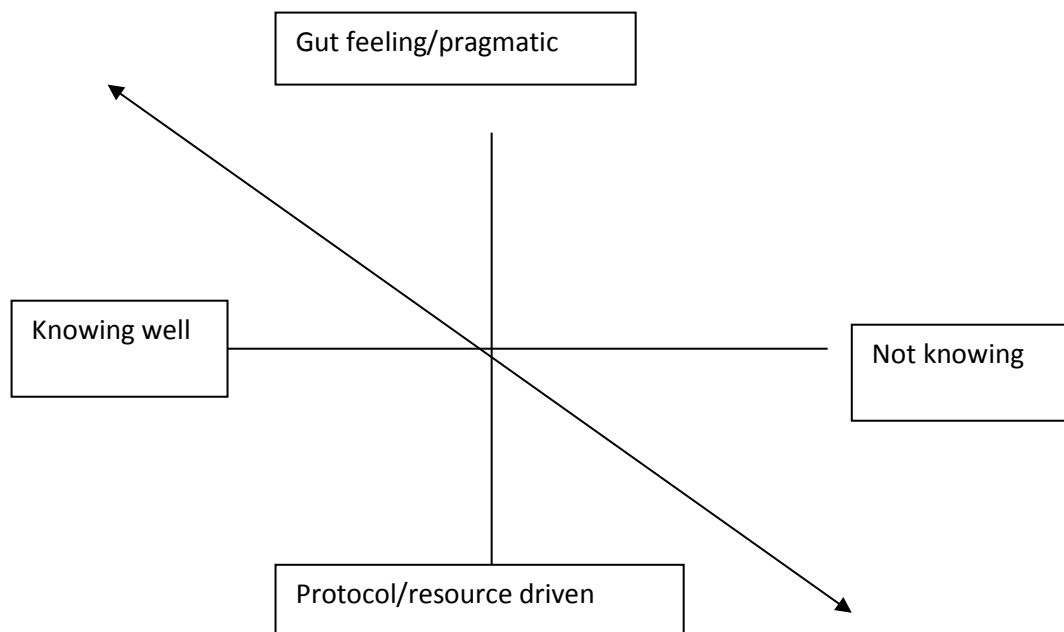
16/8/2011: (notes for discussion in supervision)

'Knowing' can consist of many factors including:

- Understanding their political/cultural/religious views
- Knowing about the cultural/religious/social factors that impact upon their lives
- Being familiar with their life story and history (putting the patient into context)
- Understanding their enduring values and beliefs
- Getting to know their pattern of behaviours in response to life events
- Understanding what they are able/unable to tolerate in life
- Being familiar with their emotional and cognitive range
- Understanding what the patient wants from life/what is important to them/key elements to their personality
- Understanding the patient's sense of humour
- Understanding the patient's boundaries
- Having an open and ongoing dialogue
- Knowing the person outside of the medical context (relevant in smaller communities)
- Seeing the patient through 'difficult times'

There are parallels here with literature on knowing the patient e.g. Tanner et al 1993 The phenomenology of knowing the patient (interviews with nurses)

Knowing the patient well may affect the type of capacity assessment that is done: the model may look a bit like this:



Knowing the patient well may have positives when it comes to capacity assessment:

- Being able to use all of the information known about the patient in the past to help to come to a decision about their capacity now
- Being able to put their current wishes into context
- To know if this decision is consistent with the individual that is known

But may also have negative implications:

- May be less 'objective'
- The assessment may be less rigorous and more may be assumed
- The professional may be at risk of colluding with the patient contrary to their best interests
- Knowing the patient may involve knowing the family well also and may put the professional in conflict with the family/community if the patient wants something different from the family

The GPs in the sample talk most about knowing the patient and the idea comes up in nearly every interview in some way.

02/09/2011 12:39 (reflective log)

Regarding theory testing with theoretical sampling would it be useful to arrange an interview focused on knowing the patient in another context and look for similarities and differences?

02/09/2011 13:49 (reflective log)

At supervision on 18th august I presented my category Knowing the patient. I had identified this as an important category which seemed to relate quite well to other categories including beliefs and values and how doctors perceive themselves and other professionals.

xxx agreed that this category was important but furthermore felt that it was appropriate to develop this as the core category.

I am still coding but will now selectively code to look at knowing the patient and codes related to this.

Main related codes appear to be:

Beliefs and values

Decision making

Impact

Perceptions

Process of capacity assessment

21/09/2011 Interview with Wales Doc_1 (field notes)

Feels that the practicalities of running an assisted dying service would create so many problems that it might be necessary to set up specialist assessment centres. Also that knowing the patient well might create biases whereby sympathy for the patients' situation might lead to less objective determinations of capacity.

Interesting idea re knowing and unknowing. Might it only be possible to successfully manage the assisted dying process if the system is set up not to know the patient too well (as seen in Oregon). The alternative would be potentially too damaging for personal and professional relationships.

26/09/2012 15:45 (reflective log)

Coding is now be selective

Main theme identified-knowing and working towards ?possible theory of distanced or detached knowing.

30/09/11 Interview with Wales Doc_2 (field notes)

Getting to know: relies on openness to the process on both sides-willingness of clinician to engage and willingness of patient to be engaged with. Something about the clinical scenario encourages openness due to intensity of situation but still some patients are 'known' better than others.

28/09/2012 14:53 (reflective log)

Initially open coding until SEGP_4 when core category identified then proceeded with selective coding of knowing.

Once core coding category identified returned to beginning to revisit coding under knowing to check (constant comparison and to check data against code and code against concept) then proceeded with selective coding of rest of data.

18/10/13 (memo)

Those doctors who explicitly acknowledged the role of personal values and tacit knowledge

spoke more about a thicker conceptualisation of capacity than those who didn't.
Even those who advocate a 'thin' process actually use values and use tacit knowledge-are they just less aware of it?

01/12/2013

Checking process of reviewing all the transcripts and checking systematically for data related to knowing the patient in order to check and develop analysis of the relationships between codes, categories and emerging theory.

**Appendix 11: Summary of studies concerning the concept of ‘knowing
the patient’ in healthcare contexts**

Author	Discipline	Publication type	Setting/Context	Elements of knowing	Stated relevance of findings
Benner and Wrubel (Benner and Wrubel J., 1989)	Nursing	Book	Exploration of the meaning of knowing the patient	A sense of knowing comes from knowing the patient's everyday habits, practices and preferences.	A sense of knowing as the basis for further assessment and intervention in nursing practice.
Swanson (Swanson, 1991)	Nursing	Qualitative study (paper)	A qualitative study of caring in three perinatal nursing contexts	Identification of five 'caring processes': being with, doing for, enabling, maintaining belief and knowing the patient. Knowing defined as 'striving to understand an event as it has meaning in the life of another'.	Knowing the patient as a fundamental caring process predicated on the nurse's philosophy of personhood and their willingness to recognise the other as a significant being.
Jenny and Logan (Jenny and Logan, 1992)	Nursing	Qualitative study (paper)	A grounded theory study of expert nursing practice during ventilator weaning	Knowing the patient as a 'cognitive and relational process whereby nurses identified salient aspects of the patient and situation while establishing their professional credibility'. Trust gained through 'knowing activities' which enhance collaboration. Empathy integral to knowing. Knowing incorporates 'esthetic, personal and moral knowing patterns'.	Identification of knowing processes leads to clinical judgments upon which intervention strategies are selected.
Tanner	Nursing	Qualitative	Interpretive	Phenomenology of knowing the	Knowing the patient identified

Author	Discipline	Publication type	Setting/Context	Elements of knowing	Stated relevance of findings
(Tanner et al., 1993)		study (paper)	phenomenological study of 130 nurses in the intensive care units of eight US hospitals. Aim to 'describe the nature of skill acquisition in nursing practice'	patient: Knowing the patient's pattern of responses, knowing the patient as a person'. Knowing the patient as a 'highly specific, situated knowledge' rather than an all-inclusive knowledge of the person.	as central to skilled clinical judgement beyond 'the instrumental application of formally based knowledge'
Radwin (Radwin, 1995b)	Nursing	Qualitative study (paper)	Grounded theory study comprising participant observation of nursing practice on a cardiology unit and 18 in depth interviews with 13 nurses	Knowing identified as a core process in the selection of therapeutic choices. Knowing identified as a 'purposeful action' where the nurse uses understanding of the patients' experience, behaviour, feelings or perceptions to select individualised interventions.	Knowing the patient is the core process in the selection of individualised interventions.
Radwin (Radwin, 1996)	Nursing	Review (paper)	A review of the literature on 'knowing the patient'. Nurses composed the samples in all but one of the reviewed studies.	Within the nursing literature three recurring factors were identified in knowing the patient: the experience of caring for patients, chronological time and a sense of closeness between patient and nurse.	Knowing the patient is important because 'it described one process by which nurses actualise a highly cherished value'. Knowing the patient 'may be characteristic of expert nurses' decision making'. Knowing the patient is relevant to 'changes in structural practice conditions in nursing' that might

Author	Discipline	Publication type	Setting/Context	Elements of knowing	Stated relevance of findings
					impede knowing.
Henderson (Henderson, 1997)	Nursing	Qualitative study (paper)	A grounded theory study of patient participation from nurses' and patients' perspectives in four Australian Hospitals	Knowing the patient emerged strongly as a factor influencing patient participation.	Knowing the patient can influence patient participation in healthcare
Luker (Luker et al., 2000)	Nursing	Qualitative study (paper)	Qualitative study of community nurses working in end of life care. Purposive sampling from four different geographical communities.	'Getting to know' identified as the 'invisible work' behind the front of physical caring. Getting to know based on three prerequisites: time, involvement and continuity of care.	Knowing the patient identified as essential to nurses' perception of providing good quality care. Purpose of getting to know identified as gaining the ability to interpret concerns and anticipate needs.
Whittemore (Whittemore, 2000)	Nursing	Editorial (paper)	Exploration of the consequences of not knowing the patient	Concern raised about the 'loss' of knowing within a healthcare environment subject to organisational rearrangement, economic constraint and systems efficiency savings. Critique of structured information gathering.	Loss of knowing forecast to have negative consequences for patient care including risks to the patient through depersonalisation of care and diminution of nurses' clinical judgment. Warns that loss of knowing may result in more costly care due to overcaution.
Charon (Charon, 2001b)	Medicine	Theoretical paper	Exploration of the concept of 'narrative medicine', introducing the concept of	Four central knowing relationships identified: between the physician and the patient, Between the	Narrative knowledge described as the basis for 'authentic engagement' in the doctor

Author	Discipline	Publication type	Setting/Context	Elements of knowing	Stated relevance of findings
			'narrative knowledge' in the doctor-patient relationship.	physician and the self, Between the physician and their colleagues and between the physician and society.	patient relationship.
Fairhurst and May 2001 (Fairhurst and May, 2001)	Medicine	Qualitative study (paper)	Qualitative study exploring ways of knowing within the doctor patient relationship through analysis of audiorecorded patient consultations with General Practitioners and subsequent interviews with the doctors.	Knowing the patient was 'crucial to the way the doctor experienced the consultation'. Two distinct ways of knowing identified: knowing about the patient and knowing the patient as a person. Facts known about the patient were thought to be less important than the way in which they came to be known. Distinction between hypothetico-deductive and inductive modes of reasoning within the consultation. Sense of knowing was linked to sense of satisfaction in the consultation.	Sense of knowing the patient is pertinent to the way General Practitioners attribute meaning to their work, especially within the ideal of continuity of care. Knowing fosters a sense of authentic engagement.
Lotzkar and Bottorff (Lotzkar and Bottorff, 2001)	Nursing	Qualitative study (paper)	Ethological study of one nurse patient dyad in oncology over three days.	Getting to know was a process engaged in by both the nurse and patient on day one and comprised introductions, general questioning proceeding to more specific and personal questioning as the day progressed.	Getting to know is a process engaged in by both nurse and patient and facilitates the development of a therapeutic relationship.
Speed and	Nursing	Qualitative	An multi site ethnographic	The nature of knowing in district	The way patients are known is

Author	Discipline	Publication type	Setting/Context	Elements of knowing	Stated relevance of findings
Luker (Speed and Luker, 2004)		study	study of the organisation of district nursing work	nursing has moved from a moral and personal paradigm to a paradigm of knowing about or knowing by proxy, owing to a change in the sociopolitical context of healthcare provision. Sense of knowing was aligned with Carper's patterns of knowing.	influenced by the sociopolitical context.
MacDonald (Macdonald, 2007)	Nursing	Qualitative study (paper)	Grounded theory study: participant observation and in depth interviews focused on interaction between nurses and patients on a family medicine nursing unit	Knowing the patient was important in developing a positive nurse patient relationship. Reconciling temporalities was a key task for nurse and patient. Time was an important factor in knowing.	Knowing the patient minimises the likelihood of difficulty in the nurse-patient encounter.
Bonis (Bonis, 2009)	Nursing	Review (paper)	Review of the concept of knowing in nursing. Identification of 103 papers with some reference to 'knowing' 'personal' and 'experience'.	97 papers identified from the nursing literature and 17 papers from the medical literature. Comment that none of the papers from the medical literature were explicitly concerned with knowing within the doctor patient relationship.	Concludes that knowing in nursing is a result of 'reflection on personal experience with the patient' whilst knowing in medicine is from a 'technical perspective'.
Crocker and Scholes (Crocker and Scholes,	Nursing	Qualitative study (paper)	An ethnographic study exploring how nurses use technology to wean patients off mechanical ventilation	The key elements of knowing the patient were continuity of care and expertise. Knowing was reliant on gaining information about the	Knowing the patient was central to nurses' perception of the delivery of patient centred care.

Author	Discipline	Publication type	Setting/Context	Elements of knowing	Stated relevance of findings
2009)				patient, with the patient as the passive recipient of care.	
Henneman (Henneman et al., 2010)	Nursing	Qualitative study (paper)	Focus group study examining strategies used by critical care nurses in US medical facilities to identify and correct medical errors	Knowing the patient was identified as one of eight strategies to identify medical errors.	Knowing the patient may influence patient safety in critical care settings.
Desjarlais-deKlerk and Wallace (Desjarlais-deKlerk and Wallace, 2013)	Medicine	Qualitative study (paper)	Grounded theory study of impact of the type of community on the doctor patient relationship. In depth interviews with four general practitioners, two working in rural and two working in suburban practice.	Two types of communication identified: 'Instrumental' (cure orientated) and 'socioemotional' (care orientated). Rural doctors used more socioemotional communication within their consultations than the suburban doctors. Rural doctors knew their patients outside of the context of the doctors office resulting in conversations reflecting the wider aspects of the relationship.	Establishment of a 'socioemotional' relationship 'may enhance patient health through establishing a trusted relationship where anything can be shared' but could be 'detrimental through an assumed knowledge of a patient's condition'.
Kelly et al (Kelley et al., 2013)	Nursing	Qualitative study (paper)	A qualitative interview study with 12 nurses working on two paediatric intensive care units in the US	The meaning of knowing the patient consisted of two broad information needs: knowing clinical information and knowing personal information about the patient.	Knowing both clinical and personal information about the patient supports nurses' ability to provide individualised patient care.
Zolnerek	Nursing	Review	Update of Radwin's 1996	Key areas of relevance for knowing	Knowing guides safe care and

Author	Discipline	Publication type	Setting/Context	Elements of knowing	Stated relevance of findings
2014 (Zolnierek, 2014)		(paper)	review of knowing the patient aiming to 'characterise the concept of knowing the patient as reflected in the nursing research literature'. Twenty one papers included in the review.	in nursing practice: care, relationships and expert practice. Model of knowing identified which takes place in a temporal environment comprising three interrelated processes: a personal process within the nurse, information practices which are translated into personal meaning, and the nursing response which includes engagement, attunement, clinical judgment and expert practice.	election of interventions. Knowing gives the nurse the ability to develop positive relationships and foster patient participation. Knowing allows the development of sound clinical judgment. Advocates that nursing training should explicitly target and foster knowing in order to improve nursing practice.

Appendix 12: Published papers

- 1. Survey of doctors opinions on the legalisation of assisted suicide**
- 2. Senior doctors' opinions on rational suicide**
- 3. Concepts of mental capacity for patients requesting assisted suicide:
A qualitative analysis of expert evidence presented to the
Commission on Assisted Dying**

Research article

Open Access

Survey of doctors' opinions of the legalisation of physician assisted suicide

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Abstract

Background: Assisted dying has wide support among the general population but there is evidence that those providing care for the dying may be less supportive. Senior doctors would be involved in implementing the proposed change in the law. We aimed to measure support for legalising physician assisted dying in a representative sample of senior doctors in England and Wales, and to assess any association between doctors' characteristics and level of support for a change in the law.

Methods: We conducted a postal survey of 1000 consultants and general practitioners randomly selected from a commercially available database. The main outcome of interest was level of agreement with any change in the law to allow physician assisted suicide.

Results: The corrected participation rate was 50%. We analysed 372 questionnaires. Respondents' views were divided: 39% were in favour of a change to the law to allow assisted suicide, 49% opposed a change and 12% neither agreed nor disagreed. Doctors who reported caring for the dying were less likely to support a change in the law. Religious belief was also associated with opposition. Gender, specialty and years in post had no significant effect.

Conclusion: More senior doctors in England and Wales oppose any step towards the legalisation of assisted dying than support this. Doctors who care for the dying were more opposed. This has implications for the ease of implementation of recently proposed legislation.

Background

Several countries or states have legislation permitting or decriminalising euthanasia or physician assisted suicide (PAS). These include Switzerland [1]; The Netherlands [2]; Belgium [3]; the US state of Oregon [4]; and, since 2008, Luxembourg [5]. These practices are legally distinct from withholding or withdrawing lifesaving or life-sustaining treatments, and from the administration of treatments which primarily aim to relieve suffering, but may incidentally also shorten life. Whilst euthanasia and PAS

are supported by 70–80% of the general population in the UK [6–9], with similar proportions being found whether the research is funded by supporters of a change in the law [8,9], by detractors [7], or by independent, disinterested groups [6], the practice remains illegal.

Groups favouring a change in the law have presented opposition to euthanasia or PAS as primarily religious [10], and one independent report commented on the apparent increase in support for legalisation as an index of

declining religious adherence [11]. In 2005, the British Medical Association voted narrowly to drop its longstanding opposition to assisted dying at its annual conference [12], but this opposition was reinstated the following year by a larger margin [13].

In recent years three attempts have been made to change the law in England and Wales to allow assisted dying for the terminally ill through Bills presented to Parliament by the human rights lawyer Lord Joffe [14]: the Patient (assisted dying) Bill in 2003 [15] and the Assisted Dying for the Terminally Ill Bill in 2004 and 2005 [16,17]. This proposed legislation is largely similar to the Death with Dignity Act of the US State of Oregon[4].

Under the terms of the Assisted Dying Bill, it would have become legal for doctors to prescribe a lethal dose of medication to patients who requested it, if the patient was diagnosed with a terminal illness, considered to be suffering unbearably, and had mental capacity to make the decision [18]. "Terminal illness" in this context means an illness which, in the opinion of two doctors, is inevitably progressive, cannot be reversed by treatment and will be likely to result in the patient's death within a few months [17]. The stipulation of possession of mental capacity was consistent with the decision being autonomous, and consistent with the values of the individual, with an absence of a disorder of mind or brain that could influence the decision-making process.

The Assisted Dying for the Terminally Ill Bill was defeated in the House of Lords in May 2006, but given the support for assisted dying by groups such as Dignity in Dying, and the state of public opinion, it is likely that a further Bill will be presented to Parliament in the future.

The proposed change in the law would affect the working practices of many senior doctors in England and Wales, but there are few peer-reviewed studies of their views. The most recent, published in 2006, surveyed the views of GPs in Wales. The response rate was 65%, the number responding was 1202, and 62% of these opposed a change in the law to allow physician assisted suicide [19]. In 1999 an attempt was made to survey all 742 members of the British Geriatrics Society and all 820 members of the Intensive Care Society. Participants were asked about their views on legalisation of assisted suicide and voluntary euthanasia, but only their opinions on the legalisation of active voluntary euthanasia were published. Eighty percent of geriatricians and 52% of intensive care doctors considered the deliberate administration of a treatment intended to kill as unjustified in any circumstance. The response rates were 45% and 37% in the two groups [20]. The views of the geriatricians from this survey had previously been published separately [21]. In 1998, 322 (72%

participation rate) UK and Irish psychiatrists were sent a questionnaire asking their views on the legalisation of assisted suicide. Forty four percent opposed a change in the law, 18% were neutral, and 38% support this [22]. In 1994, 424 GPs and hospital consultants in one area of England were asked by questionnaire whether they thought the law in the UK should be changed to allow voluntary euthanasia, similar to the situation in the Netherlands. Of the 309 (74%) doctors who returned the questionnaire and answered the question, 146 (47%) supported a change in the law, 103 (33%) opposed any change, and 60 (20%) were undecided [23]. Three of the four surveys described above showed doctors to be more opposed than in support of changes in the law to allow assisted suicide or voluntary euthanasia. The survey which showed support for a change in the law was the earliest and concerned voluntary euthanasia rather than PAS.

There are many other (non peer-reviewed) surveys of British doctors' views in the public domain, a total of fourteen of which are thoroughly reviewed in the seventh appendix of the 2005 report of the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill [24]. In addition to these is the submission to the committee by the Association for Palliative Medicine of a survey of 610 members carried out in 2003 showing 565 (93%) opposed legalising assisted suicide. No participation rate was published. The conclusion of the report is that, while the surveys should be interpreted with caution, doctors "...appear to be notably less in favour of legalising euthanasia [or PAS (implied)] than the general public." It is of note that a 2006 survey of doctors in the UK found low (2.6%) support for the idea that a new law to allow assisted dying or voluntary euthanasia would have helped real patients whose deaths they had attended, and a similarly low figure (4.6%) felt that the current legal situation interfered with the best management of patients [25].

There is evidence from Europe that health professionals, especially those who work with the dying, are similarly less supportive of a change in the law than the public: A Swiss survey contacted 726 palliative care specialists, 148 oncology clinicians and 140 medical students over the years 2000–2005. About a third of the members of professional groups were doctors, the rest being other healthcare professionals. The response rates were 56%, 59% and 'near 100%' respectively. The palliative care specialists were 44% in support of PAS, the oncology clinicians were 73% in favour, as were 77% of the medical students [26]. A 1998 Finnish survey attempted to compare the attitudes to PAS of 506 doctors, 800 nurses and 1000 members of the general public. The response rates were 62%, 68% and 59%. Twenty percent of the doctors, 34% of the nurses and 42% of the general public supported PAS in the scenario of an incurable cancer [27].

Even in countries where PAS is legal, support for this practice is far from universal among doctors. A Swiss group investigated the views of 2589 GPs, physicians, gynaecologists, oncologists and geriatricians in that country. The responders numbered 1650 (64%), and of them 32% had ever been asked to assist with a patient's suicide. Of these, 49.7% refused. Among those who had never been asked to assist with a suicide, 59% reported they would refuse [28].

There have been no published studies examining attitudes to PAS across all specialties and general practice in England and Wales, the region of jurisdiction of the proposed Bill. In this study we aimed to measure support for legalising physician assisted suicide, in any form, in a representative sample of senior doctors working in the NHS in England and Wales.

We found more doctors opposed than supported a change in the law to permit Physician Assisted Suicide, and that religious doctors were more likely to oppose such a change. Doctors who reported working frequently with the dying were also more likely to oppose a change in the law, but there was no effect of specialty, gender or years in post.

Methods

We sent questionnaires to 1000 senior doctors in England and Wales randomly sampled from the Informa Healthcare Medical Directory 2005/2006 [29], a commercially available directory of medical practitioners, available on CD-ROM. In most cases the register contained each doctor's full name, address, contact telephone number and specialty. Senior doctors were defined as currently practicing as general practitioners (GPs) or on the specialist register (consultants) in any specialty. Retired doctors were excluded.

We asked those receiving the questionnaire to provide details of their specialty, how long they had been a GP or consultant, their gender and how much their day to day work involved the management of dying people. We also asked them to rate how religious they felt they were.

We provided a brief synopsis of the Assisted Dying for the Terminally Ill Bill which included the definition of the terms used in the Bill, and a clarification of what is and is not currently legal in the UK (see additional file 1), and asked doctors to what extent they supported any change in the law towards allowing physician assisted suicide to take place in England and Wales.

Questionnaires were first sent in February 2007. A second mailing to non responders was sent 12 weeks later (May 2007). We telephoned non responders after six weeks and

resent questionnaires if required. On telephoning it was clear that a number of potential participants had moved, died or retired, and the denominator for the participation rate was adjusted to take account of this.

Each questionnaire was given a unique number, so that those who responded were not sent another questionnaire, but we removed all identifying information before the analysis.

We gained permission for the study from the Institute of Psychiatry, King's College London Research Ethics Committee.

The main outcome of interest was level of agreement with the statement: "The law should **not** be changed to allow assisted suicide". A secondary outcome was level of agreement with the statement, "I would be prepared to prescribe a fatal drug to a terminally ill patient who was suffering unbearably, were that course of action to become legal in the future". These were both ascertained using five-point Likert-type scales, which were then converted into three-point scales consisting of 'agree', 'neither agree nor disagree' and 'disagree' with legislation change to allow any form of physician assisted suicide, and with preparedness to carry out PAS, were it legal.

We performed separate univariable and multivariable analyses predicting the outcomes using polytomous methods. These are similar to logistic regression but they allow more than two outcomes to be predicted simultaneously. Covariates were gender, specialty, frequency of working with the dying, level of religiousness, years in post, and whether the respondent had read any of the Assisted Dying Bill. There were four relative risk ratios and confidence intervals produced for each exposure. For the main outcome these were disagreeing with any change in the law against agreeing with change and disagreeing with any change in the law against no opinion. For the secondary outcome the relative risk ratios represented not being prepared to carry out PAS were it legal against being prepared to do so, and not being prepared to carry out PAS against reporting no opinion.

Results

A response rate of 50% was achieved once we had accounted for exclusions (Figure 1). We found no differences between responders and non-responders (Table 1).

Most of the responders (93% – not shown) filled in all or nearly all of the questionnaire, leaving three or less of the 50 items blank.

Thirty-two percent of responding doctors reported having read at least some of the Bill. This did not differ by spe-

Table 1: Characteristics of sample.

	Participants			Refusers			Non Responders			Total		
Specialty	Male N (%)	Female N (%)	Total N (%)	Male N (%)	Female N (%)	Total N (%)	Male N (%)	Female N (%)	Total N (%)	Male N (%)	Female N (%)	Total N (%)
GP	118(46)	70(60)	188(51)	65(51)	25(61)	90(53)	64(45)	39(75)	103(53)	247(47)	134(64)	381(52)
Medical	60(23)	30(26)	90(24)	25(20)	8(20)	33(20)	30(21)	8(15)	38(20)	115(22)	46(22)	161(22)
Surgical	45(18)	2(2)	47(13)	22(17)	1(2)	23(14)	29(20)	2(4)	31(16)	96(18)	5(2)	101(14)
Psych	18(7)	10(9)	28(8)	4(3)	3(7)	7(4)	6(4)	0(0)	6(3)	28(5)	13(6)	41(6)
Other	15(6)	4(3)	19(5)	10(8)	2(5)	12(7)	10(7)	2(4)	12(6)	35(7)	8(4)	43(6)
Unknown	0(0)	0(0)	0(0)	2(2)	2(5)	4(2)	3(2)	1(2)	4(2)	5(1)	3(1)	8(1)
Total	256(69)	116(31)	372(51)	128(76)	41(24)	169(23)	142(73)	52(27)	194(26)	526(72)	209(28)	735(100)

Note: Percentages within the body of the table are column percentages. Within the Total row of the table they are row percentages within supercolumns, with the exception of those also within the Total columns, which are row percentages between supercolumns. Eg 118/256=46%, 256/372=69% and 372/735=51%.

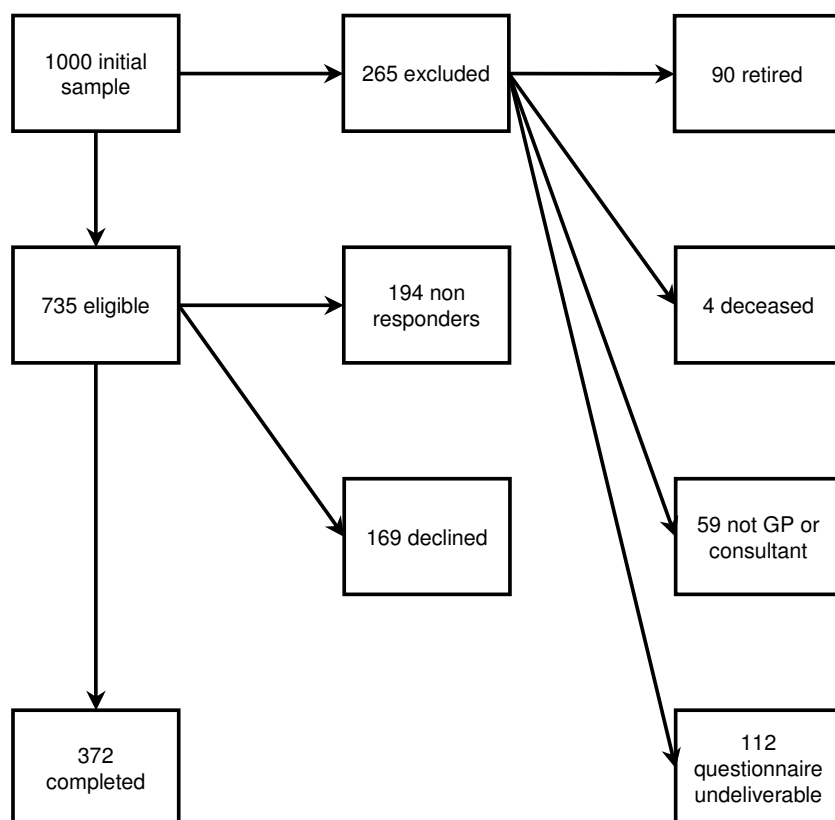


Figure 1
Outcomes of the sample of senior doctors initially contacted.

cialty (34% to 39%), except for surgical specialties, who were much less likely to have read the Bill (15%). Female doctors reported having read at least some of the Bill more frequently than male doctors (42% vs 27%).

Overall, 39% (95% CI: 34% to 44%) of the sample supported changing the law to permit PAS, 49% (44% to 54%) were opposed to a change and 12% (7% to 15%) neither agreed nor disagreed with any change. Most supporters of change in the law endorsed the option to 'agree' with some legislative step towards physician assisted suicide, whereas most doctors who were opposed to a change endorsed 'disagree strongly' (Figure 2).

Gender, specialty and years in post had no effect on support for or opposition to new law. The only significant associations were amount of time spent working with the dying, religiousness, and having read at least some of the Bill. Those doctors who spent more time caring for the dying were less likely to support a change in the law. Greater strength of religious belief was also associated with opposition to a change, as was having read at least some of the Bill (Table 2). These three variables acted independently of one another (Table 3). While less religious doctors were more likely to support a change in the law, an appreciable proportion of these (34% for "no religion" and 47% for "not very religious") were opposed to a change. A smaller proportion of religious doctors sup-

ported a change in the law (15% for "very religious" and 32% for "fairly religious").

Respondents more frequently supported a change in the law (38%) than indicated they, personally, would facilitate PAS (31%) ($z = 2.22$ $P = 0.027$). There was no association between gender and being prepared to facilitate PAS. Those who worked with the dying, rated themselves as more religious, and had read at least some of the Bill were less likely to report being prepared to assist in PAS. These effects were robust to the effects of correcting for the other exposures as potential confounders (Table 4). There was some evidence that GPs were less likely to assist in PAS than hospital consultants, and that doctors who had been in post longer were more likely to be prepared to assist, but these effects were abolished when the confounders were taken into account. There was a strong, but incomplete, relationship between supporting the idea of assisted dying and being prepared to facilitate this process were it to become legal (Table 4).

Discussion

Senior doctors are divided in their views about a change in the law to allow PAS, and fewer are in favour than are the general public in the UK [6,9]. This finding has been observed in the US [30-33], Canada [34], Finland [27] and the Netherlands [35], but this is the first survey that seeks to ascertain whether this is also true of a representative sample of senior doctors in England and Wales. Fur-

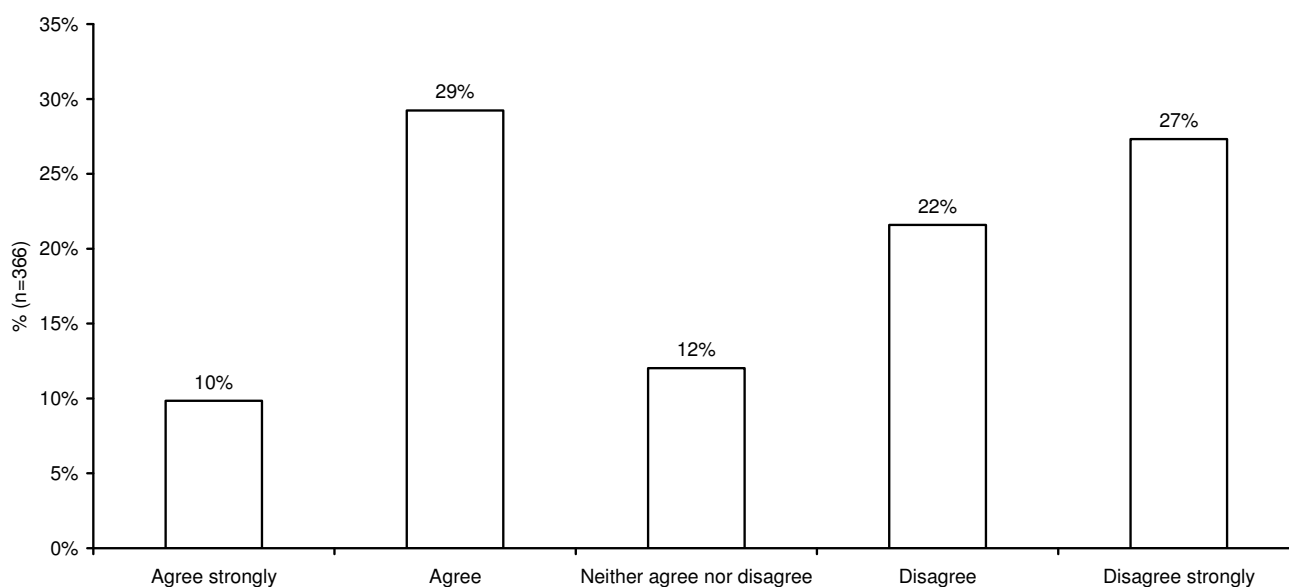


Figure 2

Views of senior doctors on the legalisation of physician assisted suicide. More doctors oppose PAS (49%) than support it (39%), and the opposition is more opposed to the Bill than the support is in favour of it.

Table 2: Raw data cross-tabulations of various factors with doctors views on physician assisted suicide and on whether they would assist in suicides were it legal to do so.

		Support PAS				Would consider PAS if legal			
		Agree	Neither agree nor disagree	Disagree	Missing	Agree	Neither agree nor disagree	Disagree	Missing
		N	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Sex	Male	256	95(37)	31(12)	126(49)	4(2)	82(32)	32(13)	139(54)
	Female	116	48(41)	13(11)	53(46)	2(2)	33(28)	15(13)	67(58)
		<i>Chi2 = 0.65 df = 3 P = 0.89</i>				<i>Chi2 = 0.59 df = 3 P = 0.90</i>			
Specialty	Consultant	184	77(42)	21(11)	84(46)	2(1)	64(35)	29(16)	90(49)
	GP	188	66(35)	23(12)	95(51)	4(2)	51(27)	18(9)	116(62)
		<i>Chi2 = 2.23 df = 3 P = 0.53</i>				<i>Chi2 = 8.28 df = 3 P = 0.04</i>			
Care for dying	Daily	30	9(30)	2(7)	18(60)	1(3)	8(27)	2(7)	20(66)
	Weekly	77	21(27)	9(12)	45(58)	2(3)	15(20)	7(9)	54(70)
	Monthly	116	39(34)	15(13)	61(52)	1(1)	40(35)	12(10)	63(54)
	Yearly	72	33(46)	12(17)	27(37)	0(0)	22(31)	15(21)	35(49)
	<Yearly	37	15(41)	2(5)	18(49)	2(5)	11(30)	6(16)	20(54)
	Never	35	23(66)	4(11)	8(23)	0(0)	19(54)	4(11)	11(32)
	Missing	5	3(60)	0(0)	2(40)	0(0)	0(0)	1(20)	3(60)
		<i>Chi2 = 32.3 df = 18 P = 0.02</i>				<i>Chi2 = 45.5 df = 18 P < 0.0005</i>			
Religious	No	110	57(51)	15(14)	38(34)	1(1)	54(49)	14(12)	43(39)
	Not very	121	44(36)	18(15)	57(47)	2(2)	36(30)	23(19)	61(50)
	Fairly	102	33(32)	11(11)	57(56)	1(1)	23(22)	8(8)	70(69)
	Very	27	4(15)	0(0)	23(85)	0(0)	0(0)	1(4)	26(96)
	Missing	11	5(46)	0(0)	4(36)	2(18)	2(18)	1(9)	6(55)
		<i>Chi2 = 49.3 df = 12 P < 0.0005</i>				<i>Chi2 = 79.1 df = 12 P < 0.0005</i>			
Years in post	0-	33	11(33)	7(21)	14(43)	1(3)	7(21)	5(15)	21(64)
	10-	160	66(41)	18(11)	75(47)	1(1)	50(31)	22(14)	87(54)
	20-	127	39(31)	12(9)	72(57)	4(3)	36(28)	16(13)	74(58)
	30-	48	25(52)	7(15)	16(33)	0(0)	22(46)	3(8)	21(44)
	Missing	4	2(50)	0(0)	2(50)	0(0)	0(0)	0(0)	3(75)
		<i>Chi2 = 17.4 df = 12 P = 0.14</i>				<i>Chi2 = 32.1 df = 12 P = 0.001</i>			
Looked at Bill	No	252	108(43)	34(13)	105(42)	5(2)	85(34)	36(14)	130(52)
	Yes	118	34(29)	10(8)	74(63)	0(0)	30(25)	11(9)	75(64)
	Missing	2	1(50)	0(0)	0(0)	1(50)	0(0)	0(0)	1(50)
		<i>Chi2 = 45.7 df = 6 P < 0.0005</i>				<i>Chi2 = 52.3 df = 6 P < 0.0005</i>			
Support PAS	Agree	143	143(100)	0(0)	0(0)	0(0)	74(52)	27(19)	40(28)
	Neither	44	0(0)	44(100)	0(0)	0(0)	16(36)	11(25)	17(39)
	Disagree	179	0(0)	0(0)	179(100)	0(0)	24(13)	9(5)	145(81)
	Missing	6	0(0)	0(0)	0(0)	6(100)	1(17)	0(0)	4(66)
						N/A	<i>Chi2 = 114.9 df = 6 P < 0.0005</i>		
Total:		372	143(38)	44(12)	179(48)	6(2)	115(31)	47(13)	206(55)
									4(1)

Note: Tests significant at the 5% level are shown in **bold**.

Table 3: Associations of various factors with doctors' views on physician assisted suicide.

		N	Crude Relative Risks (95% CIs)		Corrected Relative Risks (95% CIs)	
			Disagree vs Agree	Disagree vs Neither	Disagree vs Agree	Disagree vs Neither
Sex	Male	256	1.00	1.00	1.00	1.00
	Female	116	0.83 (0.52 to 1.34)	1.00 (0.49 to 2.07)	0.63 (0.36 to 1.08)	0.85 (0.39 to 1.84)
Specialty	Consultant	184	1.00	1.00	1.00	1.00
	GP	188	1.32 (0.85 to 2.05)	1.03 (0.53 to 2.00)	1.03 (0.60 to 1.77)	0.74 (0.35 to 1.60)
Care for dying	Daily	30	1.00	1.00	1.00	1.00
	Weekly	77	1.07 (0.41 to 2.78)	0.56 (0.11 to 2.83)	0.92 (0.34 to 2.54)	0.47 (0.09 to 2.48)
	Monthly	116	0.78 (0.32 to 1.91)	0.45 (0.09 to 2.16)	0.78 (0.30 to 2.01)	0.42 (0.09 to 2.09)
	Yearly	72	0.41 (0.16 to 1.06)	0.25 (0.05 to 1.25)	0.38 (0.14 to 1.04)	0.22 (0.04 to 1.15)
	<Yearly	37	0.60 (0.21 to 1.72)	1.00 (0.13 to 7.89)	0.73 (0.24 to 2.21)	1.06 (0.13 to 8.60)
	Never	35	0.17 (0.06 to 0.54)	0.22 (0.03 to 1.47)	0.18 (0.05 to 0.58)	0.21 (0.03 to 1.43)
	Missing	5	0.33 (0.05 to 2.37)	Empty Cell	Empty Cell	Empty Cell
			Test for trend: $P < 0.0005$	Test for trend: $P = 0.17$	Test for trend: $P = 0.001$	Test for trend: $P = 0.20$
Religious	No	110	1.00	1.00	1.00	1.00
	Not very	121	1.94 (1.10 to 3.43)	1.25 (0.56 to 2.78)	1.81 (1.00 to 3.25)	1.23 (0.55 to 2.76)
	Fairly	102	2.59 (1.43 to 4.69)	2.05 (0.85 to 4.93)	2.47 (1.31 to 4.65)	1.84 (0.74 to 4.54)
	Very	27	8.63 (2.76 to 26.92)	Empty Cell	10.01 (2.67 to 37.6)	Empty Cell
	Missing	11	1.20 (0.30 to 4.76)	Empty Cell	0.61 (0.13 to 2.82)	Empty Cell
			Test for trend: $P < 0.0005$	Test for trend: $P < 0.004$	Test for trend: $P < 0.0005$	Test for trend: $P = 0.01$
Years in post	0-	33	1.00	1.00	1.00	1.00
	10-	160	0.89 (0.38 to 2.10)	2.08 (0.73 to 5.91)	0.84 (0.33 to 2.09)	2.15 (0.72 to 6.40)
	20-	127	1.45 (0.60 to 3.50)	3.00 (1.00 to 8.96)	1.29 (0.49 to 3.39)	3.25 (0.99 to 10.64)
	30-	48	0.50 (0.18 to 1.38)	1.14 (0.32 to 4.07)	0.59 (0.19 to 1.79)	1.37 (0.34 to 5.43)
	Missing	4	0.79 (0.09 to 6.50)	Empty Cell	Empty Cell	Empty Cell
			Test for trend: $P < 0.634$	Test for trend: $P = 0.58$	Test for trend: $P = 0.83$	Test for trend: $P = 0.47$
Looked at Bill	No	252	1.00	1.00	1.00	1.00
	Yes	118	2.24 (1.3 to 3.64)	2.40 (1.11 to 5.15)	1.70 (0.99 to 2.92)	1.80 (0.81 to 4.01)
	Missing	2	Empty Cell	Empty Cell	Empty Cell	Empty Cell
Total:		372				

Note 1: Tests for trend exclude the rows representing missing values.

Note 2: Tests and estimates significant at the 5% level are shown in bold.

ther, we found that doctors who had more day to day experience of working with the dying were more strongly opposed, as were those who rated themselves as religious.

One explanation for our findings among those who work frequently with the dying could be that it is the strong culture of palliative care in the UK which has resulted in the responding doctors being opposed to a change in the law to allow assisted suicide. There were only six respondents in the survey who reported their speciality, even in part, as palliative care and all six were opposed to a change in the law. Excluding them from the analysis however, made no substantial change to the findings (not shown).

The views of doctors who do not care for the dying are more like those of the general public, with 66% of those never caring for the dying supporting a change in the law,

whilst 72% of those caring for the dying on a daily basis oppose it. This difference is not accounted for by stronger religious beliefs in those who care for the dying. Doctors who had read at least some of the Bill were more opposed to legalisation, an effect which was independent of religion and having a role in caring for the dying. It may be that greater knowledge of the proposed law influenced views, but is perhaps more likely that those most opposed take a greater interest in the debate.

Could it be that doctors' opposition to a change in the law stems from an over-optimistic belief in their ability to relieve suffering for the dying? The finding that the doctors who regularly care for the dying are more opposed than those who do not, argues against this view. It suggests instead that intimate knowledge and clinical experi-

Table 4: Associations of various factors with whether doctors would assist suicide were it legal to do so.

		N	Crude Relative Risks (95% CIs)		Corrected Relative Risks (95% CIs)	
			Disagree vs Agree	Disagree vs Neither	Disagree vs Agree	Disagree vs Neither
Sex	Male	256	1.00	1.00	1.00	1.00
	Female	116	1.20 (0.73 to 1.97)	1.03 (0.52 to 2.03)	0.85 (0.48 to 1.51)	0.75 (0.36 to 1.59)
Specialty	Consultant	184	1.00	1.00	1.00	1.00
	GP	188	1.62 (1.02 to 2.56)	2.08 (1.08 to 3.98)	1.39 (0.79 to 2.45)	1.60 (0.74 to 3.44)
Care for dying	Daily	30	1.00	1.00	1.00	1.00
	Weekly	77	1.44 (0.53 to 3.91)	0.77 (0.15 to 4.03)	1.24 (0.42 to 3.65)	0.71 (0.13 to 3.98)
	Monthly	116	0.63 (0.25 to 1.57)	0.52 (0.11 to 2.55)	0.53 (0.20 to 1.44)	0.40 (0.08 to 2.03)
	Yearly	72	0.64 (0.24 to 1.69)	0.23 (0.05 to 1.13)	0.60 (0.21 to 1.73)	0.20 (0.04 to 1.01)
	<Yearly	37	0.73 (0.24 to 2.19)	0.33 (0.06 to 1.85)	0.89 (0.27 to 2.94)	0.37 (0.06 to 2.16)
	Never	35	0.23 (0.08 to 0.70)	0.27 (0.04 to 1.75)	0.30 (0.09 to 1.00)	0.34 (0.05 to 2.26)
	Missing	5	Empty Cell	0.30 (0.02 to 4.42)	Empty Cell	Empty Cell
			Test for trend: <i>P</i> = 0.001	Test for trend: <i>P</i> = 0.015	Test for trend: <i>P</i> = 0.024	Test for trend: <i>P</i> = 0.061
Religious	No	110	1.00	1.00	1.00	1.00
	Not very	121	2.13 (1.20 to 3.78)	0.86 (0.40 to 1.87)	2.07 (1.14 to 3.74)	0.77 (0.35 to 1.70)
	Fairly	102	3.82 (2.06 to 7.09)	2.85 (1.10 to 7.35)	3.47 (1.82 to 6.64)	2.54 (0.95 to 6.76)
	Very	27	Empty Cell	8.47 (1.05 to 68.2)	Empty Cell	Empty Cell
	Missing	11	3.77 (0.72 to 19.61)	1.95 (0.22 to 17.65)	2.82 (0.50 to 16.0)	1.23 (0.13 to 11.93)
			Test for trend: <i>P</i> < 0.0005	Test for trend: <i>P</i> = 0.002	Test for trend: <i>P</i> < 0.0005	Test for trend: <i>P</i> = 0.003
Years in post	0-	33	1.00	1.00	1.00	1.00
	10-	160	0.58 (0.23 to 1.46)	0.94 (0.32 to 2.78)	0.46 (0.17 to 1.26)	0.77 (0.25 to 2.42)
	20-	127	0.69 (0.27 to 1.76)	1.10 (0.36 to 3.36)	0.44 (0.15 to 1.25)	0.66 (0.20 to 2.23)
	30-	48	0.32 (0.11 to 0.90)	1.25 (0.29 to 5.31)	0.32 (0.10 to 1.04)	1.40 (0.27 to 7.30)
	Missing	4	Empty Cell	Empty Cell	Empty Cell	Empty Cell
			Test for trend: <i>P</i> = 0.086	Test for trend: <i>P</i> = 0.63	Test for trend: <i>P</i> = 0.10	Test for trend: <i>P</i> = 0.90
Looked at Bill	No	252	1.00	1.00	1.00	1.00
	Yes	118	1.63 (0.99 to 2.71)	1.89 (0.91 to 3.93)	1.27 (0.72 to 2.26)	1.39 (0.63 to 3.03)
	Missing	2	Empty Cell	Empty Cell	Empty Cell	Empty Cell
Total:		372				

Note 1: Tests for trend exclude the rows representing missing values.

Note 2: Tests and estimates significant at the 5% level are shown in bold.

ence of patients who are dying negatively influences views about PAS.

Fewer doctors stated that they were prepared to facilitate PAS if legalised, than were in favour of a change in the law. Some doctors who opposed any change in the law but stated they were prepared to facilitate physician assisted suicide were it to become legal, but there were more who supported a legal change but would not be prepared to carry out the act if permitted under law.

We have compared the findings of our study with surveys examining the views of the general public. Surveys of this subject are vulnerable to over- or under-estimation due to insufficient explanation of concepts and question choice which makes one answer more likely than others, meaning that their findings should not necessarily be accepted

uncritically. As an example, the YouGov poll [9] is criticised for both issues because there is no explanation that an act of shortening a patients life has to be deliberately intended to kill for it to be considered physician assisted suicide within the meaning of most assisted dying laws, and the question about it asks "...do you think the law should be changed to allow [appropriate] patients to receive a prescription from their doctor to end their suffering, subject to a range of safeguards?". The similarity of estimates of support for PAS between surveys, however, does suggest that the general population seems to be more in favour of than opposed to the introduction of assisted dying legislation in the UK.

The responders and non-responders in the sample were similar on all of the criteria we were able to measure, suggesting no serious problem of response bias within the

sample (Table 1). The Medical Directory claims to contain the details of more than 120,000 practicing doctors. Figures obtained from the General Medical Council GMC show approximately 250,000 doctors currently registered in the UK (Personal Communication by telephone 01/01/2006). The doctors in the sample may not be typical of doctors as a whole due to the voluntary nature of registering with a commercial provider, and the possible undesirable effects (in the form of unsolicited promotional material) of being included. Further, the database was not up to date, containing relatively few newly registered GPs or specialists (Table 2). These problems noted, we have no reason to believe this database is inferior in this regard than any other source of postal addresses of practicing UK doctors straightforwardly available to researchers. In addition, any effect of years in post was taken into account in the multivariable analyses.

The response rate of 50% was disappointing but is superior to similar surveys [20,21]. Efforts we made to boost the response rate included a personalised and individually signed letter, a repeat mailing, and personal telephone follow up [36]. Incentives such as money or gifts do marginally boost response rates, but this course was rejected because of ethical considerations and concerns over data quality. A shorter questionnaire may have resulted in a greater response rate, but this would have contained fewer data, and evidence suggests that the response rate only rises when the questionnaire is kept to a single page [36].

We suggest that qualitative research is required to understand doctors' views better. The opposition of doctors most closely involved in the care of the dying to a change in the law may pose a practical difficulty for implementing any new legislation, since under the terms of the Bill, those likely to be most involved in the process of assessment prior to assisted suicide are more opposed to a change in the law.

Conclusion

We showed that senior doctors in the England and Wales are divided over the issue of physician assisted suicide, with more opposing than supporting any change in the law to allow this practice. This is at variance with the results of surveys of the general public which show a high and stable degree of support. Thirty one percent of the doctors questioned would be prepared to facilitate assisted suicide were it legalised, which has implications for policy makers and for those considering how this practice might be implemented were it to become law.

Competing interests

WL, AP and MH have all experience of working in a palliative care setting. MH, WL, AP and LR do not have any religious affiliation. MH was on the Royal College of Psy-

chiatrists working group on Assisted Dying, and during a consultation run by the College, voiced concern about a change in the law based on his experience of caring for people requesting assisted dying.

Authors' contributions

Every task associated with this paper was carried out by one or more of the authors. The original idea for the study was by MH and WL. WL gained ethical approval, carried out the database work and drafted the questionnaire. WL and AP shared the administrative tasks associated with the mailings. Telephone follow ups were carried out by AP and WL. LR organised the returned questionnaires and carried out the data entry. WL, AP and LR carried out the analysis. AP and LR drafted the paper initially and all authors contributed to the manuscript. MH supervised all of the above processes. All authors read and approved the final manuscript.

Additional material

Additional file 1

Appendix. The synopsis of the Assisted Dying Bill, the definition of terms and the used questions from the questionnaire sent to participants.

Click here for file

[<http://www.biomedcentral.com/content/supplementary/1472-6939-10-2-S1.doc>]

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PAPER

Senior doctors' opinions of rational suicide

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ABSTRACT

Context The attitudes of medical professionals towards physician assisted dying have been widely discussed. Less explored is the level of agreement among physicians on the possibility of 'rational suicide'—a considered suicide act made by a sound mind and a precondition of assisted dying legislation.

Objective To assess attitudes towards rational suicide in a representative sample of senior doctors in England and Wales.

Methods A postal survey was conducted of 1000 consultants and general practitioners randomly selected from a commercially available database. The main outcome of interest was level of agreement with a statement about rational suicide.

Results The corrected participation rate was 50%; 363 questionnaires were analysed. Overall 72% of doctors agreed with the possibility of rational suicide, 17% disagreed, and 11% were neutral. Doctors who identified themselves as being more religious were more likely to disagree. Some doctors who disagreed with legalisation of physician assisted suicide nevertheless agreed with the concept of rational suicide.

Conclusions Most senior doctors in England and Wales feel that rational suicide is possible. There was no association with specialty. Strong religious belief was associated with disagreement, although levels of agreement were still high in people reporting the strongest religious belief. Most doctors who were opposed to physician assisted suicide believed that rational suicide was possible, suggesting that some medical opposition is best explained by other factors such as concerns of assessment and protection of vulnerable patients.

INTRODUCTION

The WHO has estimated that approximately a million people die by suicide worldwide every year.¹ Many studies indicate that most people who commit suicide have a disturbance of mental functioning.² This is consistent with there being some people who wish for death, but do not have any impairment of mind. For these people, public health approaches intended to prevent suicide, largely concerned with the elimination of the means by which suicide might be carried out, might be considered infringements on individual liberty. Indeed, the current illegality of UK doctors prescribing medications intended to bring about death represents an unacceptable limit on personal choice for some groups.^{3 4}

Societal trends towards secularism have accompanied shifts in the judgement of suicide from

being a moral or religious failure in need of prohibition by the state towards a situation where most suicides have come to be seen as the result of disturbance of mind viewed in a morally neutral manner.² This was exemplified in the UK by the decriminalisation of the act of suicide in 1961.⁵ Consistent with these wider trends, contemporary developments in palliative care encourage and afford more opportunity for terminally ill people to contemplate the place and manner of their own deaths.⁶

Philosophical and theological debates about the morality of suicide are probably as old as human history. Among the Western classics, for example, Plato and the Stoics took contrasting positions on the permissibility of suicide, with Plato arguing that it disgraced the human and the Stoics arguing for its permissibility. Among world religions, Christianity, Judaism and Islam have tended to strongly prohibit suicide, whereas Eastern religions such as Buddhism and Jainism have not. Contrasting accounts of suicide may be found in the thoughts of St Thomas Aquinas and David Hume.⁷ Aquinas argued that suicide was contrary to natural law and to charity. Part of his argument was that, because every person belongs to a community, self-killing injures the community. David Hume doubted Aquinas' concepts of natural law and charity and thought that, in some circumstances, suicide satisfies both the individual's primary needs and the larger public interest.

Werth and Holdwick have suggested circumscribed criteria under which suicides should not be prevented.⁸ The proposals are that, for a suicide to be considered rational (and therefore worthy of not being prevented), the person in question must have an unremittingly hopeless medical condition, should make their decision as a free choice, have engaged in a sound decision-making process, and there should have been an assessment by a mental health professional. Proposed criteria for the circumstances under which assisted suicide should be allowable are similar and are also of relevance. Beauchamp⁷ proposes that assisted suicide could be appropriate with capable patients, where there is mutual decision-making by patient and physician. The decision should be made in a reflective and supportive environment and there should be an ongoing patient–physician relationship. A considered rejection of alternatives is necessary. These criteria are similar to those in unsuccessful attempts to change the law in England and Wales to allow physician assisted suicide (PSA).⁹

Research examining attitudes concerning end of life decisions has focused on those towards assisted

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dying, and the pragmatic issue of whether it is appropriate for the law to allow physicians to prescribe medication for this purpose. With this in mind, an examination of the possibility of rational suicide is of worth, as rational suicide is a logical prerequisite for assisted dying to be morally defensible. That is, if a doctor finds it ethical to bring about the death of a patient at the explicit request of that patient, he or she is showing their belief in the possibility of rational suicide.

Many international surveys have found general populations to be in broad agreement with the legalisation of assisted dying in one form or another (reviewed by a 2005 parliamentary report on the subject¹⁰). All current and proposed legislation for assisted dying around the world involves medical practitioners. However, doctors are divided, with a majority opposing such legalisation.^{11 12} Campaigners have identified medical opposition as a key obstacle to legalisation of assisted dying.¹³

There has been little exploration into the views of physicians concerning rational suicide. In a survey of members of the Royal College of Psychiatrists, Shah *et al*¹⁴ found that 86% of respondents agreed that suicide could be rational, while 7% were neutral and 7% disagreed, a finding they found curious when contrasted against the previous finding that about 90% of people who commit suicide have a mental illness.² Surveys of attitudes to rational suicide have been undertaken across a range of non-medical health professionals. Werth and Holdwick reviewed the literature in 2000 and found 70–80% acceptability for both rational suicide and physician assisted death. They also found that 20–40% of mental health professionals have had experience working with patients whom they considered to hold suicidal plans that they considered rational.⁸

Given that belief in rational suicide is a prerequisite for supporting assisted dying legislation, and that decisions on the subject of assisted dying, were it to become legal, are likely to involve senior doctors, we aimed to survey senior doctors practising in England and Wales about their attitudes towards rational suicide and to identify any relationships between these attitudes and other factors such as religious belief and medical specialty.

METHOD

We sent questionnaires to 1000 senior doctors in England and Wales, who were randomly sampled from the Informa Healthcare Medical Directory 2005/2006, a commercially available directory of medical practitioners. For our purposes, a 'senior doctor' was defined as someone who is currently practising as a general practitioner (GP) or a doctor on the specialist register (consultant in the UK) working in any specialty. Retired doctors were excluded, as were directory entries with inadequate postal address information. Other results from this study regarding PSA have already been published elsewhere.¹¹

When completing the survey, we asked those receiving the questionnaire to provide details of their specialty, how long they had been a GP or consultant, their gender, and how much their day to day work involved the management of dying people. We also asked them to record how religious they considered themselves to be. Questionnaires were first posted in February 2007, and non-responders received the questionnaire again 12 weeks later. After a further 6 weeks, we telephoned non-responders, resending questionnaires as required. If it became clear that a potential subject was unable to participate in the survey for reasons of moving, retirement or death, the denominator for the participation rate was adjusted to take account of this. Each questionnaire was given a unique identifying number so that those who responded were not sent another questionnaire. We removed all identifying information before the analysis.

The main outcome of interest was level of agreement with the statement: 'suicidality cannot be rational under any circumstances'. This was ascertained using a five-point Likert-type scale, which was then converted into a three-point scale consisting of 'agree', 'neither agree nor disagree' and 'disagree' with the possibility of rational suicide.

We gained permission for the study from the Joint Maudsley Hospital and Institute of Psychiatry Research Ethics Committee (Ref 06/Q0706/36).

RESULTS

A response rate of 50% (372/735) was achieved once we had accounted for exclusions (265). We found no differences between responders and non-responders for specialty¹¹ (not shown).

Overall, 72% of the sample agreed that suicide can be rational (table 1), 17% disagreed, and 11% neither agreed nor disagreed. There were no statistically significant differences in the view of rational suicide by specialty. Level of agreement with rational suicide was negatively related to the intensity of religious belief. Responders who reported themselves to be minimally religious were the most in agreement with rational suicide (84%). Responders who considered themselves to be most religious

Table 1 Degree of support for the possibility of rational suicide by various factors

Factor	Agree	Neither	Disagree	Total
Total	263 (72)	39 (11)	61 (17)	363 (100)
Gender*				
Male	181 (73)	29 (12)	37 (15)	247 (69)
Female	79 (71)	10 (9)	23 (20)	112 (31)
	$\chi^2=2.1$, df=2, p=0.36			
Specialty				
GP	127 (70)	20 (11)	34 (19)	181 (50)
Medical	62 (70)	12 (14)	14 (16)	88 (24)
Surgical	33 (70)	5 (11)	9 (19)	47 (13)
Psychiatry	25 (89)	1 (4)	2 (7)	28 (8)
Other	16 (84)	1 (5)	2 (11)	19 (5)
	Fisher exact test: p=0.65			
How religious*				
1 Min	93 (84)	8 (7)	10 (9)	111 (31)
2	85 (71)	14 (12)	20 (17)	119 (34)
3	64 (65)	12 (12)	22 (22)	98 (28)
4 Max	15 (56)	4 (15)	8 (30)	27 (8)
	Trend test Z=3.7, p=0.0002			
Care for dying*				
Daily	23 (80)	3 (10)	3 (10)	29 (8)
Weekly	55 (73)	8 (11)	12 (16)	75 (21)
Monthly	79 (70)	13 (12)	20 (18)	112 (31)
Yearly	43 (61)	11 (15)	17 (24)	71 (20)
<Yearly	27 (73)	3 (8)	7 (19)	37 (10)
Never	33 (94)	1 (3)	1 (3)	35 (10)
	Trend test Z=-0.80, p=0.42			
Physician assisted dying*				
Agree	120 (86)	6 (4)	13 (9)	139 (39)
Neither	27 (61)	9 (20)	8 (18)	43 (12)
Disagree	116 (66)	24 (14)	37 (21)	143 (40)
	Trend test Z=3.95, p<0.0001			

Values are number (%).

*Owing to partial missing data, the denominator for the gender, degree of religiousness, frequency of caring for the dying, and physician assisted dying questions was reduced from 363 to 359, 355, 359 and 359, respectively (<2.5%).

Statistical tests were Pearson χ^2 except where an expected value was <5, when Fisher exact test was used.

GP, general practitioner.

were in least agreement (56%). There was no relationship between the frequency of caring for dying patients and view of the possibility of rational suicide.

Doctors who approve of legislation to legalise PAS were more in agreement with the possibility of rational suicide (86%) than those who disagreed with PAS (66%).

We carried out multivariable logistic regression to assess independent predictors of agreement with rational suicide. The two other conditions of disagreeing with the possibility of rational suicide and having no view were combined into a single comparison group. The only independent associations were that doctors who were more religious were more opposed to the possibility of rational suicide, as were doctors who disagreed with legalisation of physician assisted dying (table 2). The tests for trend across the groups were $Z=-2.64$ $p=0.008$ for religiousness and $Z=-3.04$ $p=0.002$ for support for PSA.

DISCUSSION

Most (72%) of our sample of senior doctors in England and Wales reported thinking that rational suicide is possible. There was no significant effect of gender or specialty, but the stronger a doctor reported their religious beliefs to be, the more they were predisposed to disagreement with rational suicide, although even in the most religious group there was only 30% disagreement. This is consistent with other research.¹⁵ Unsurprisingly, doctors in support of assisted dying were more likely to report thinking that rational suicide is possible.

This and other samples have previously shown that doctors are divided over assisted dying legislation, with a majority opposed to changing the law to permit this practice.^{11 12} The opposition of doctors to assisted dying cannot now be explained

by this group believing that suicide can never be rational. Other explanations may be the view that it would be impossible in practice to select only those people who rationally wish for suicide, while ensuring vulnerable people receive the protection they need. Second, they may oppose assisted dying legislation because the prospect of medical involvement in bringing about deaths is professionally unacceptable. Third, doctors may feel that suicide, rational or not, is morally prohibited for religious or other reasons.

This study does not allow for straightforward differentiation between these potential explanations. The psychiatrists in our sample, presumably the doctors with the most experience and training in managing suicidal patients, were as supportive of the possibility of rational suicide as the rest of the sample. Indeed, this specialty was the most in agreement with the possibility, although the difference was not statistically significant. A study only examining the views of psychiatrists had a similar finding of 86% of respondents agreeing that rational suicide is possible.¹⁴ Previously we have found greater experience of caring for dying patients to be strongly associated with increasing opposition to the legalisation of PAS,¹¹ so it is of interest that greater experience of suicidal patients (as indexed by being a psychiatrist) is not strongly associated with views either for or against the possibility of rational suicide.

As well as the many doctors who agree with the possibility of rational suicide but do not support a change in the law to allow PAS, we noted that some (13 (3.6%)) who opposed the possibility of rationality of suicide nevertheless supported the legalisation of PSA, itself a process to facilitate rational suicides. This could have been because of poor understanding of assisted dying legislation as recently proposed, because of poor appreciation of the questions, or possibly the participants were answering on their view of lethal prescribing for incapacitated individuals, which is not the subject of this paper nor a subject of current mainstream debate in any jurisdiction.

The main strength of this survey is that it was undertaken on a large representative sample of senior UK doctors and contained a single question on the morality of suicide which we think has face validity. The responders and non-responders in the sample were similar on the criteria available (gender and specialty), suggesting no serious problem of response bias. Attitudes of doctors to the idea of rational suicide have been little studied, and not at all in the UK during recent debates on the legalisation of PSA.

This study has some weaknesses. The question on the possible 'rationality' of suicide is arguably distinct from the morality of suicide. If 'rationality' is interpreted purely as a morally neutral mental ability, then it is possible to believe that suicide may be 'rational' but morally impermissible in a similar way to how a certain crime may be seen as rational but still morally impermissible. Probing these subtle distinctions in a questionnaire design, however, we think would be challenging. Contemporary ideas emphasising patient autonomy may influence doctors to select more liberal answers than those which would reflect the views they actually hold; however, were this true, then more liberal answers to the questions about PSA would be expected.

The response rate was modest at 50%. A shorter questionnaire may have resulted in a higher response rate, but this would have meant the collection of fewer important covariates. The doctors in the sample may not be representative of doctors as a whole because of registering with a commercial provider being voluntary. The database was also not up to date, containing relatively few newly registered GPs or specialists. However, we have no

Table 2 Multivariable logistic regression of associations with support for the notion of rational suicide

Variable	Frequency (%)	Crude OR (95% CI)	Corrected OR (95% CI)
Gender			
Male	247 (68)	1.00 (ref)	1.00 (ref)
Female	112 (31)	0.87 (0.53 to 1.43)	1.07 (0.61 to 1.89)
Specialty			
GP	181 (50)	1.00 (ref)	1.00 (ref)
Medical	88 (24)	1.01 (0.58 to 1.77)	0.84 (0.45 to 1.58)
Surgical	47 (13)	1.00 (0.50 to 2.02)	0.93 (0.41 to 2.11)
Psychiatry	28 (8)	3.54 (1.03 to 12.23)	1.69 (0.43 to 6.61)
Other	19 (5)	2.27 (0.63 to 8.10)	0.67 (0.15 to 3.05)
How religious			
1 Min	111 (31)	1.00 (ref)	1.00 (ref)
2	119 (33)	0.48 (0.25 to 0.92)	0.65 (0.32 to 1.29)
3	98 (27)	0.36 (0.19 to 0.70)	0.44 (0.21 to 0.89)
4 Max	27 (7)	0.24 (0.10 to 0.60)	0.28 (0.10 to 0.76)
Care for dying			
Daily	29 (8)	1.00 (ref)	1.00 (ref)
>Weekly	75 (21)	0.72 (0.26 to 2.02)	0.93 (0.30 to 2.84)
>Monthly	112 (31)	0.62 (0.23 to 1.67)	0.65 (0.22 to 1.86)
>Yearly	71 (20)	0.40 (0.14 to 1.11)	0.34 (0.11 to 1.02)
<Yearly	37 (10)	0.70 (0.22 to 2.24)	0.67 (0.18 to 2.42)
Never	35 (10)	4.30 (0.80 to 23.25)	3.34 (0.55 to 20.33)
Physician assisted dying			
Agree	139 (38)	1.00 (ref)	1.00 (ref)
Neither	43 (12)	0.24 (0.11 to 0.53)	0.24 (0.11 to 0.56)
Disagree	177 (49)	0.30 (0.17 to 0.53)	0.35 (0.18 to 0.67)

The crude estimates are calculated on the denominators detailed in table 1. The adjusted estimates are on the 348 (96%) participants who had complete data for all the variables. Bold type indicates $P<0.05$.

GP, general practitioner.

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reason to believe that this database is inferior in this regard to any other source of details of practising UK doctors readily available to researchers.

We have shown that most senior doctors in England and Wales believe that suicide can be rational. More strongly held religious beliefs were associated with opposition to rational suicide, although, even here, levels of opposition were not high. Further research is needed to investigate the reasons for medical opposition to PAS in light of this. The reasons are likely to concern the problems, in practice, that doctors see in selecting only those people who rationally wish for suicide (a group they may see as small), while giving vulnerable people the protection they need (a group they may see as large). There may also be concerns about the social implications of doctors becoming explicitly linked to a phenomenon that has historically been associated with considerable community suffering and stigma. More detailed questionnaire studies may assist such understanding. Qualitative research could assist the development of such questionnaires and could also allow a deeper understanding of doctor's views on the morality of suicide, as its moral permissibility is also presupposed by the laws on assisted dying currently enacted internationally, as well as the recent proposed legal changes in England and Wales. Such interviews should include doctors with religious belief.

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Competing interests None.

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Contributors SG conceived the study and drafted the manuscript. AP, LR, RDH, GSO, MH and WL contributed to the study design, manuscript redrafting and made specific academic contributions. WL executed the analysis and supervised the project throughout. All authors have approved the final manuscript.

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RESEARCH ARTICLE

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Concepts of mental capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence presented to the Commission on Assisted Dying

Annabel Price^{1*}, Ruaidhri McCormack², Theresa Wiseman³ and Matthew Hotopf⁴

Abstract

Background: In May 2013 a new Assisted Dying Bill was tabled in the House of Lords and is currently scheduled for a second reading in May 2014. The Bill was informed by the report of the Commission on Assisted Dying which itself was informed by evidence presented by invited experts.

This study aims to explore how the experts presenting evidence to the Commission on Assisted Dying conceptualised mental capacity for patients requesting assisted suicide and examine these concepts particularly in relation to the principles of the Mental Capacity Act 2005.

Methods: This study was a secondary qualitative analysis of 36 transcripts of oral evidence and 12 pieces of written evidence submitted by invited experts to the Commission on Assisted Dying using a framework approach.

Results: There was agreement on the importance of mental capacity as a central safeguard in proposed assisted dying legislation. Concepts of mental capacity, however, were inconsistent. There was a tendency towards a conceptual and clinical shift toward a presumption of incapacity. This appeared to be based on the belief that assisted suicide should only be open to those with a high degree of mental capacity to make the decision. The 'boundaries' around the definition of mental capacity appeared to be on a continuum between a circumscribed legal 'cognitive' definition of capacity (in which most applicants would be found to have capacity unless significantly cognitively impaired) and a more inclusive definition which would take into account wider concepts such as autonomy, rationality, voluntariness and decision specific factors such as motivation for decision making.

Conclusion: Ideas presented to the Commission on Assisted Dying about mental capacity as it relates to assisted suicide were inconsistent and in a number of cases at variance with the principles of the Mental Capacity Act 2005. Further work needs to be done to establish a consensus as to what constitutes capacity for this decision and whether current legal frameworks are able to support clinicians in determining capacity for this group.

Keywords: Assisted suicide, Mental capacity, Qualitative

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Background

Assisting suicide remains illegal in England and Wales following three unsuccessful attempts to pass Bills to legalise the practice in 2003 [1], 2004 [2] and 2005 [3]. In 2012 a new draft Bill '*Safeguarding Choice: A Draft Assisted Dying Bill for Consultation*' [4] was published, and in May 2013 a new Assisted Dying Bill to '*Enable competent adults who are terminally ill to be provided at their request with specified assistance to end their own life; and for connected purposes*' was tabled in the House of Lords by Lord Falconer [5]. The Bill is currently scheduled for a second reading in the House of Lords in May 2014. Mental capacity is once again proposed as a key safeguard and the Bill stipulates that the Secretary of State may issue one or more codes of practice in connection with '*assessing whether someone has the capacity to make such a decision*' and '*recognising and taking account of the effects of depression or other psychological disorders that may impair a person's decision-making*'. Mental capacity is construed in the Bill in accordance with the Mental Capacity Act 2005 [6].

Prior to the drafting of the new Bill, the "Commission on Assisted Dying", hosted by DEMOS (a think tank focussed on power and politics) [7], funded by author Sir Terry Pratchett and businessman Bernard Lewis (both proponents of assisted dying) and chaired by Lord Falconer was convened in September 2010. Its stated aims were to consider whether the current legal and policy approach to assisted dying in England and Wales was '*fit for purpose*' and to '*explore the question of what a framework for assisted dying might look like, if such a system were to be implemented in the UK, and what approach to assisted dying might be most acceptable to health and social care professionals and to the general public*' [8]. After gathering evidence, the Commission published its findings in early 2012 entitled '*The current legal status of assisted suicide is inadequate and incoherent*' and recommended the provision of the choice of assisted dying for mentally competent adults with terminal illness [9]. The Commission proposed eligibility criteria to be met in order to proceed with a request for assisted dying. These comprised (i) the presence of terminal illness; (ii) that the decision should be voluntary; and (iii) that "*(t)he person has the mental capacity to make a voluntary and informed choice, and the person's decision making is not significantly impaired as a result of mental health problems such as depression*".

In line with the new Bill, the report emphasised establishment of mental competence as a central safeguard in any legal process allowing assisted suicide. The Commission concluded that assessment of mental capacity for every eligible patient requesting assisted suicide should be undertaken, primarily by doctors, and that the relevant professional bodies should be responsible for developing a

code of practice for the assessment of mental capacity. The Mental Capacity Act 2005 was invoked as the framework within which mental capacity should be assessed. The Act, which sets out criteria for a test of capacity aims to help clinicians to preserve patient autonomy for those who are able to make their own decisions and allow care to be provided in the best interests of those who lack this capacity. The Act rests on five key principles, including, "*a person must be assumed to have capacity unless it is established that they lack capacity*" and "*a person is not to be treated as unable to make a decision merely because he makes an unwise decision*". The Act requires that an individual is able to understand and retain the information necessary to make a decision, as well as use and weigh that information to arrive at a decision and then be able to communicate the decision once made.

Whilst, according to the Mental Capacity Act, the legal definition of (a lack of) capacity is precise, the application of the definition in clinical practice is less clear cut. Difficulties exist in assessing and operationalising how a patient uses and weighs information and how affective states impact on capacity [10-12]. These areas may be open to influence by individual factors in both the patient and the assessing clinician(s) [13] and it has been argued that capacity determination is intrinsically value laden [14], in line with many aspects of decision making in psychiatry [15]. The potential for a broad range of opinion in individual cases was exemplified by the debate surrounding the decisions made in the case of Kerrie Woollorton, a 26 year old woman who died in 2007 after drinking antifreeze and refusing life saving treatment having been determined to have capacity by the treating team [16].

Whilst the dimensions of capacity exist on a continuum, determination of mental competence is binary. Thresholds for competence are influenced by how much risk is incurred by the decision being made, with high risk decisions requiring 'greater' capacity or margin for error [17] as established in English Law by Lord Donaldson in the case of *re T* (Adult: Refusal of treatment) [18]. This view is controversial however as it has been suggested that it opens the door for medical paternalism [19]. This debate has a potential impact on practice in assisted suicide - in a survey of US forensic psychiatrists, those with ethical objections to assisted suicide recommended higher thresholds for competence and a more extensive review of the decision [20].

The safeguards proposed in the 2013 Assisted Dying Bill have been informed by the findings published in the Commission on Assisted Dying report, which in turn was informed by the expert evidence given to the Commission. With these ethical, legal and clinical challenges in mind, and considering what might best inform the development of codes of practice on capacity assessment, this study aims to explore how the experts presenting

this evidence conceptualised mental capacity for patients requesting assisted suicide and examine these concepts particularly in relation to the principles of the Mental Capacity Act 2005.

Methods

The Commission on Assisted Dying invited experts drawn from 'a wide range of backgrounds' [21] to present oral evidence. Thirty seven interviews with 50 experts were video recorded and transcribed. In addition, 13 pieces of written evidence were submitted and published alongside the oral evidence. Two of the authors of this study (AP and MH) submitted one piece of written evidence [22] and gave oral evidence to the Commission [23,24]; these submissions advised caution around the use of mental capacity as a safeguard for assisted suicide. These two pieces of evidence were excluded from analysis; therefore our sample comprised 36 transcripts of oral evidence and twelve pieces of written evidence.

Secondary analysis of the transcripts used a framework approach [25] and comprised four phases: 1) Two researchers (AP and RM) independently familiarised themselves with the data by reading the transcripts and written evidence and watching the videotaped evidence submissions 2) A thematic framework was developed by identifying key issues and concepts present in the data 3) Concepts and themes occurring in the data were discussed and important areas were agreed upon and further discussed with the other members of the research team (MH and TW) before a final agreement was reached 4) Focussed coding of the data was conducted and the main concepts and recurring themes present in the data further defined and refined.

Ethical approval for the study was not required as the data is published in the public domain.

Results

The 36 oral and 12 written submissions analysed included evidence given by a wide range of experts including 12 medical and social care professionals, eight legal professionals, two persons with disability, four current and former carers/family members, seven academics, three faith group leaders, nine representatives of advocate groups and seven representatives of professional bodies. Of the 15 organisations represented at the Commission, four stated a position in favour of a change in the law to allow assisted suicide, two stated a position against, one stated a position of neutrality and eight did not state a position. Of the clinicians giving evidence, three had specific mental health clinical training (one consultant psychiatrist and two clinical psychologists).

Of the 36 oral evidence submissions, 33 included some reference to mental capacity or issues related to assessment of mental capacity. Of the three submissions that

did not refer to mental capacity for patients requesting assisted suicide or related issues, one was from a medical regulatory body which focussed on the current status of assistance of suicide as unlawful and did not enter into discussion regarding safeguarding including mental capacity [submission 20], one was from a medical defence organisation where the discussion focused on doctors' concerns around the 2010 Director of Public Prosecutions guidance on assisted suicide [submission 14], and one focused on current government policy on end of life care [submission 18]. Table 1 provides a summary of the experts who provided evidence to the Commission.

Summary of findings

The key themes presented are: 1) The importance of mental capacity in assisted dying legislation; 2) Defining mental capacity, including the boundaries of the concept of mental capacity, 3) The impact of depression on mental capacity 4) Rationality and altruistic assisted suicide and 5) Presumption of capacity. Other themes identified include processes of mental capacity assessment and risks of mental capacity assessment for people requesting assisted suicide and will be presented elsewhere.

The importance of mental capacity in assisted dying legislation

Where discussed it was unanimously felt that mental capacity should be an important safeguard in any assisted suicide legislation. Assisted suicide for those lacking mental capacity to make the decision was not felt to be appropriate by any of the experts nor was a system allowing advanced decision making to choose assisted suicide for patients who subsequently lost capacity e.g., *'That decision [in the best interests of someone who lack capacity] of course is not even an issue in the debate about legislation on assisted dying because this legislation is not intended to be of any relevance to people who do not have the capacity to choose and decide'* [Submission 21].

The central importance of mental capacity as a safeguard in assisted suicide legislation was emphasised particularly by those who stated a clear position in support of assisted suicide, for example, representatives of Health Professionals for Assisted Dying stated the importance of mental capacity five times during their oral submission and representatives of Dignity in Dying stated this four times e.g., *'I hope we have made it clear that we would want any assisted dying process to include a rigorous process to ensure that somebody only could do this if they meet the criteria, including capacity'* [Submission 24].

Definition and boundaries of the concept of mental capacity

Whilst the majority of experts made reference to mental capacity in their submissions, few explicitly defined it.

Table 1 Summary of experts presenting evidence to the Commission on Assisted Dying

	Name	Role	Organisation represented (if applicable)	Type of evidence	Further relevant information
1	DI Adrian Todd DC Michelle Cook	Police Officers	West Mercia Police force	Oral	Investigated the assisted suicide of Daniel James
2	Christine Kalus Dr Rebecca Coles-Gale	Clinical Psychologists in specialist palliative care, Portsmouth City PCT and the Rowans Hospice	British Psychological Society	Oral and written	
3	Joyce Robbins	Patient advocate	Patient concern	Oral	Position in favour of a change in the law to allow assisted suicide
4	Baron Joel Joffe	Lawyer Labour Peer House of Lords		Oral and written	Proponent of 2004 and 2005 Assisted Dying for the Terminally Ill Bills
5	Chris Broad			Oral	Wife Michelle Broad ended her own life in 2010 after being diagnosed with terminal cancer
6	Dr Richard Huxtable Dr Martin Curtice	Senior Lecturer and Deputy Director for the Centre of Ethics in Medicine, University of Bristol Consultant in old age psychiatry, Holyhill Unit, Birmingham	Centre for Ethics in Medicine	Oral	Position in favour of no change in the current law
7	Martin Green	Chief Executive	The English Community Care Association	Oral	No stated organisational position on assisted suicide
8	Dr Ann McPherson Dr Ray Tallis Professor Joe Collier	Chair Deputy Chair	Healthcare Professionals for Assisted Dying	Oral and written	HPAD was founded in 2010 and has approximately 400 members
9	Gary Fitzgerald		Action on elder abuse	Oral	No stated organisational position on assisted suicide
10	David Congdon	Head of Campaigns and Policy	MENCAP	Oral	Organisation opposed to change in the law to allow assisted suicide
11	Andrew Copson	Chief executive	British Humanist Association	Oral and written	Organisation in favour of a change in the law to allow assisted suicide
12	Alan Cutkelvin Rees			Oral	Partner ended his life by assisted suicide at Dignitas in 2007
13	Suzy Croft	Senior Social Worker, St John's Hospice		Oral and written	
14	Dr Stephanie Bown* Dr Lillian Field*	Director of Policy and Communications Medicolegal advisor	Medical Protection Society	Oral	Organisation neutral on a change in the law to allow assisted suicide
15	Bridget Robb	Development Manager	British Association of Social Workers	Oral and written	No stated organisational position on assisted suicide
16	Pauline Smith	End of life care and dementia lead	NHS West Midlands	Oral	No stated organisational position on assisted suicide
17	Professor Tim Maughan	Consultant Oncologist and Professor of Cancer Studies Cardiff University		Oral	

Table 1 Summary of experts presenting evidence to the Commission on Assisted Dying (Continued)

18	Professor Sir Mike Richards*	National Clinical Director for cancer and End of Life Care	Department of Health	Oral	No stated organisational position on assisted suicide
19	Professor Michael Bennett	Professor of Palliative Medicine, International Observatory on End of Life Care, Lancaster University		Oral	
20	Paul Philip*	Deputy Chief Executive		Oral	
	Jane O'Brien*	Head of Standards and Ethics	General Medical Council		No stated organisational position on assisted suicide
21	Baroness Onora O'Neill	Professor of Philosophy University of Cambridge Cross bench member House of Lords		Oral	
22	Peter Bailey	Trustee Leonard Cheshire disability		Oral	Not representing the organisation-giving evidence in a private capacity
23	Baroness Mary Warnock	Independent cross bench member of the House of Lords.		Oral	Active supporter of legalisation of assisted suicide for the terminally ill.
24	Sarah Wootton Davina Hehir	Chief Executive Head of Policy	Dignity in Dying	Oral	Organisation in favour of a change in the law to allow assisted suicide
25	Rabbi Danny Rich	Chief Executive Liberal Judaism		Oral	Not representing the organisation-giving evidence in a private capacity
26	Reverend Professor Robin Gill	Professor of Applied Theology, University of Kent		Oral	Not representing the organisation-giving evidence in a private capacity
27	Keir Starmer QC	Director of Public Prosecutions	Crown Prosecution Service	Oral	
28	Professor Clive Seale	Professor of Medical Sociology, Barts and the London School of Medicine and Dentistry		Oral and written	
29	Dr Adrian Tookman	Consultant in palliative medicine, Royal Free Hospital, Hampstead and Medical Director, Marie Curie Hospice.		Oral	
30	Richard Hawkes Alice Maynard	Chief Executive Chair	SCOPE	Oral	Organisation opposed to change in the law to allow assisted suicide
31	Jane Nicklinson Saimo Chahal	Wife of Tony Nicklinson, who at the time of the commission was seeking assisted suicide Solicitor (Representing Tony Nicklinson) with written statements from Tony Nicklinson)		Oral and written (one written 'Scheme for assisted death' and two written statements read out in oral evidence)	
32	Debbie Purdy Omar Puente	Campaigners for legalisation of assisted suicide Husband of Debbie Purdy		Oral	
33	Professor Penney Lewis	Professor of Law, School of Law, King's College London		Oral and written (written evidence co-authored by Geneva Richardson and Roger Brownsword, School of Law, KCL)	
34	Simon Gillespie	Chief Executive	Multiple Sclerosis Society	Oral	No stated organisational position on assisted suicide

Table 1 Summary of experts presenting evidence to the Commission on Assisted Dying (Continued)

35	Lucy Scott Moncrieff Robert Robinson	Solicitor, Mental Health Tribunal Judge Solicitor	Scott-Moncrieff & Associates LLP	Oral and written	
36	Dr Andrew McCulloch	Chief Executive	Mental Health Foundation	Oral	No stated organisational position on assisted suicide

*No discussion of mental capacity in written or oral evidence.

Only in seven submissions were any direct questions asked by the panel regarding capacity, and none of the experts were asked to give a definition. For those who did define mental capacity, it was described variously as being 'of sound mind', possessing 'rational autonomy' having a 'robust wish', 'full understanding' and being 'able to make their own mind up...'. The terms 'capacity', 'competence' and in one case 'consent' appeared to be used with the same intended meaning. There did not appear to be a clear distinction between the definitions used by clinicians compared with non-clinicians, between professional groups, or between those in favour of or opposed to assisted suicide.

The findings showed that where described, conceptualisations of mental capacity were on a spectrum. At one end was a tightly defined 'cognitive' or 'intellectual' conceptualisation, whilst at the other was a broader conceptualisation involving a number of components, e.g., '*...it does show a fundamental flaw with our thinking about capacity - that it's clearly a sort of intellectual function, and it is not. It's a holistic function, a combination of the intellectual, emotional, perceptual and so on and how that reasoning comes together*' [Submission 36].

Of the 10 submissions in which an explicit conceptualisation of mental capacity was described, five presented a cognitive/intellectual conceptualisation and five a broader conceptualisation. Of the five presenting a cognitive/intellectual conceptualisation, three stated a position strongly in favour of the legalisation of assisted suicide [Submissions 3, 4, 8] and of those describing a broader conceptualisation, none stated a personal or organisational position regarding the legalisation of assisted suicide [Submissions 2, 9, 21, 26, 36].

The impact of depression on mental capacity

The range of boundary conceptualisations was particularly illustrated when examining the interface between mental state and mental capacity, with the relationship between the decision to request assisted suicide and depression a particular area of inconsistency. There appeared to be a prevailing sense that this was a difficult area in mental capacity determination and in particular that separating the normal emotional response to life limiting illness and an abnormal mental state is problematic. There was inconsistency in the views presented as to whether depressive symptoms (either as a clinical depressive syndrome or reactive depressive symptoms in response to terminal illness) would impact negatively on one's capacity to make this decision e.g., '*Now major depression in itself, if you apply the Mental Capacity Act, does not automatically mean you lack capacity, but it's highly likely to influence your decision-making*' [Submission 6] vs '*Obviously you expect that a person who is dying might feel quite sad about that and that's a different thing*

to depression, then that's a different thing again to whether or not somebody has capacity' [Submission 25].

It was unclear from the evidence what severity of depression would be considered likely to have an impact upon capacitous decision making and how this might be determined. Some felt that any depression might impact upon decision making capacity, '*Yes it can do, I mean depression can affect one's capacity to make decisions or to behave emotionally, cognitively, behaviourally, in all sorts of ways*' [Submission 2], whilst others thought that a finding of depression would almost always be consistent with capacity if only a cognitive test of capacity were applied, e.g., '*...a majority of depressed patients will meet that test [the Mental Capacity Act test of capacity], so we can't rely on those requests related factors to deal with the victim who is suffering from depression or some other mental disorder*' [Submission 33].

Rationality and altruistic assisted suicide

The findings also showed that for a number of experts, wider concepts including autonomy, rationality, voluntariness and motivating factors behind the decision were felt to be integrally related to mental capacity and would need to be explored as part of a comprehensive assessment of decision making ability. This was illustrated particularly in the range of opinions on the concept of 'altruistic assisted suicide'. Some experts felt that it was appropriate and consistent with capacity to decide that one's continued life is a burden to others and decide to seek assisted suicide with the intention of relieving them of that burden e.g., '*I think there are all sorts of pressures that are going to influence your decision and some of them get sort of hauled out as how this is terrible, you feel you're a burden. Well, I don't want to be a burden; I think an altruistic choice is a perfectly reasonable choice*' [Submission 3], whilst for others, rationality appeared to be synonymous with capacity and was felt to be incompatible with choosing assisted suicide to reduce burden on others, '*When is the person making the decision rationally, or because they feel they don't want to be a burden on their family?*' [Submission 24] Other experts felt that altruistic motives were not acceptable as motivating factors and if identified should be a barrier to assisted suicide e.g., '*...in a sense, what you're looking for here is that the person's reasons are selfish, that they're doing it for themselves, not for somebody else*' [Submission 35].

Presumption of capacity

Whilst presumption of capacity was cited by a number of experts as an important cornerstone in thinking about mental capacity assessment e.g., '*... obviously the starting point would be of presumed capacity under the Mental Capacity Act*' [Submission 6], a number of experts felt that a formal assessment of capacity should take place

for every patient making a request e.g., *'I hope we have made it clear that we would want any assisted dying process to include a rigorous process to ensure that somebody only could do this if they meet the criteria, including capacity'* [Submission 24].

There appeared to be a lack of consistency in whether the assessment was required to prove that the individual possessed or lacked capacity for the decision: possession of mental capacity was cited as an inclusion criterion for assisted suicide by some, e.g., *'I mean it is quite clear to us that there are some fundamental points. Firstly, making sure that the person truly does have capacity'*. [Submission 24] whilst lack of capacity was cited as an exclusion criterion by others: *'So this would exclude, for example... assisted dying for someone who doesn't have mental capacity...'* [Submission 8].

There was variability in the perceived relationship between presumption of capacity and the appropriate use of Mental Capacity Act as an assessment framework as shown in Table 2. Only two experts who advocated for the use of the Mental Capacity Act made a clear statement that mental capacity for assisted suicide should be presumed; a further nine either explicitly stated that they would not presume capacity, made contradictory statements within their submission or made unclear statements about whether capacity should be presumed. Of the five experts who made clear statements that capacity should be presumed, two advocated the use of the Mental Capacity Act, one made a clear statement that the Mental Capacity Act was inadequate for use in assessing capacity in this circumstance, one was unclear on whether the Mental Capacity Act was a suitable framework and one did not discuss the assessment framework in their submission.

Discussion

The report published by the Commission on Assisted Dying advocates a change in the law to allow assisted suicide and cites possession of the mental capacity to make a request as a *'key element that should underpin a safeguarded framework for assisted dying'*; but this assertion is based on evidence that presents unclear and inconsistent concepts of mental capacity and little discussion about the standards and frameworks that should be used to assess this capacity.

Within the submitted evidence there were two key areas of consistency among the experts. Firstly that mental capacity should be a central safeguard and secondly that advance decision making for those likely to lose capacity in the future is not appropriate for assisted suicide: capacity should be present at the time the decision is being made. But between and sometimes within expert submissions, there was a lack of consistency in the definition and boundaries of the concept of mental capacity, and the interface of capacity with other areas that might have a bearing upon its determination, particularly motivation, voluntariness, autonomy, rationality and the presence and severity of mental disorder, specifically depression.

The Commission on Assisted Dying has strongly recommended that any assisted suicide legislation be closely regulated and safeguarded. Mental capacity determination as set out in the Mental Capacity Act 2005 has surface validity for fulfilling this safeguarding role but deeper exploration of the evidence informing these recommendations shows that the ways in which mental capacity is conceptualised are diverse. Several of the experts expressed ideas that were not consistent with the principles of the Mental Capacity Act, particularly the presumption of capacity.

The Act makes it clear that if there is no demonstrable disorder of mind or brain then the patient is free to make whatever decision they choose regardless of whether this is wise, unwise or no decision is made at all. In order for the Commission to recommend assessment of capacity for all patients there may be an implicit normative judgment about the decision to request assisted suicide being strongly indicative of a disorder of mind or brain, but this potentially introduces a problem—that the decision itself implies that capacity may be impaired but in order to proceed with assisted suicide it must be demonstrated that it is not. The conceptual shift toward demonstrating presence rather than lack of capacity, reflected in the recommendation from the Commission that capacity be assessed formally in all cases is also potentially problematic because within the Mental Capacity Act there is no clear definition of mental capacity (only a lack of capacity) and no clarity or guidelines on what would

Table 2 Relationship between presumption of capacity and endorsement of the use of the Mental Capacity Act 2005

		Presumption of capacity				
		Yes	No	Unclear/both*	Not discussed	Total
Mental Capacity Act	Yes	2	1	4	2	9
	No	1	0	0	0	1
	Unclear	1	0	2	0	3
	Not discussed	1	1	1	17	20
	Total	5	2	7	19	33

*Within one expert submission there are statements which suggest both presumption and non-presumption of capacity.

constitute sufficient mental capacity to decide to undergo assisted suicide.

The Mental Capacity Act 2005 test of capacity only applies to England and Wales. Internationally, most jurisdictions base their capacity laws on a 'functional' approach which is decision and time specific rather than 'outcome' or 'status' based approach and capacity is presumed; [26] however, different jurisdictions use different components for capacity determination; for example in the US, the capacity test is based on national case law and evaluates dimensions of 'understanding', 'appreciation', 'reasoning' and 'expressing' a choice. Also, there are a number of instruments used to assess capacity [27] for example the Macarthur Competency Assessment Tool (MacCAT-T) developed in the US [28].

Of the jurisdictions internationally where assisted suicide is legal, all include mental capacity as part of their safeguards [29] but only the Oregon and Washington statutes give an explicit definition of mental capacity [30]. Guidelines for mental health professionals accompanying the Oregon Death with Dignity Act (DWDA) outline the capacity evaluation process, but these acknowledge that this process is difficult, especially in determining the impact of mental disorders on decision making ability [31].

Challenges in mental capacity determination are not unique to the situation of assisted suicide. In healthcare, both refusals (e.g., refusal of further life sustaining treatment) and requests (e.g., requests for gender reassignment or living organ donation) require a determination of mental capacity which can often involve detailed and wide-ranging assessment in order to reach a satisfactory conclusion. Assessment of factors such as motivation and voluntariness will often form part of a comprehensive assessment of decision making in these circumstances.

In her paper examining mental capacity using an anthropological approach, Doorn [32] argues that the available literature focuses on criteria for the assessment of competence without elaborating on what it is to be competent or incompetent to make a decision. She describes 'thin' and 'thick' conceptualisations of capacity which correspond to a more cognitive conceptualisation based on 'negative' autonomy (self determination with freedom from the interference from others) and a richer conceptualisation which acknowledges values (both of the patient and clinician) and is based on 'positive' autonomy (the potential for self development and fulfilment). She argues that assessment tools used to measure capacity have their roots in a 'thin' conceptualisation which does not acknowledge the 'value ladenness' of capacity decisions but rely on narrower cognitive abilities. This view is not without criticism [33,34] but is echoed by other authors who argue that a value neutral or value free conceptualisation of capacity is potentially problematic in practice [14] and that capacity assessment is inherently

normative and irreducible to a set of objective criteria [35]. The findings of this study showed that a cognitive conceptualisation was more frequently endorsed by those strongly in favour of assisted suicide which would appear to be consistent with the value of self-determination, but among the experts there were a number of normative judgements being made about reasons for requesting assisted suicide e.g. being a burden on others. Ideas about 'reasonable' and 'unreasonable' reasons for requesting assisted suicide further emphasise the subjectivity potentially inherent in the process.

The interface between mental state and mental capacity continues to present challenges and this issue is far from resolved. Even within an assessment framework emphasising cognitive elements of mental capacity, depression may have a significant bearing in terms of their ability to use and weigh the relevant information, but how far this might be tolerated and the patient still be found competent to make the decision to request assisted suicide remains unclear.

Depression is common in palliative care [36] and desire for hastened death is strongly associated with depression in palliative populations [37]. In Oregon it has been shown that depression is not always appropriately identified in patients requesting assisted suicide [38]. There is evidence to suggest that treatment of depression can reduce the wish for hastened death [39] and that antidepressants are effective in patients with life threatening illness [40].

Strengths and limitations

This study analysed data that were not originally gathered for the purpose of examining concepts of mental capacity. This could be seen as both a limitation and a strength. Because the study used secondary analysis of these data there was no opportunity to further examine concepts or directly compare similar data. Had they been interviewed with mental capacity as the main focus, the experts may have presented different ideas and perspectives and different conclusions may have been reached. However, the strength of these data is that they provided an opportunity to examine the experts' 'naturalistic' ideas about capacity and to analyse the points of convergence with and divergence from current legal, clinical and philosophical constructs.

The experts presenting to the Commission were invited by the Commissioners because of particular interest or expertise in areas related to the subject being examined. Few were experts in mental health and even fewer experts in mental capacity determination. This sample can therefore not be considered to be representative of current thinking about mental capacity but the responses do show a range of ideas about mental capacity from several different backgrounds, disciplines and ethical standpoints.

The authors acknowledge that one's ethical standpoint on the legalisation of assisted suicide can have a bearing on individual ideas about mental capacity, particularly the standard required for possession of capacity [20]. Reflexivity is an important element of analytic rigour in qualitative methodology [41] which allows the research to be placed in appropriate context so that conclusions can be judged in light of this context. The researchers analysing and reporting this data have a particular interest in mental capacity assessment and three of the authors (AP, MH and RMC) are clinicians who frequently assess mental capacity as part of their roles and are familiar with the challenges of applying the legal framework of the Mental Capacity Act 2005 in complex clinical situations including end of life decision making. We take the position that legalisation of assisted suicide is a matter for society to decide through due parliamentary process but AP and MH have previously expressed concerns about mental capacity as a safeguard in assisted dying legislation in part due to a concern about the potential for subjectivity and normativity in the process and outcome of clinical assessment [10]. One of the authors (MH) has undertaken a review of reliability in mental capacity assessment and found that this is good when rigorous assessment procedures are applied but less so for less structured clinical assessments [42]. MH has also commented previously on the difficulties of clearly defining mental capacity due to its varying conceptualisation as a legal, clinical or social construct and differing definitions across jurisdictions [17].

Conclusions

The Mental Capacity Act was originally conceived as a statutory framework to protect those who lack capacity to make decisions for themselves and provide a mechanism by which others can make decisions on their behalf in their best interests. Clinically the model fits quite well in situations where patients are refusing proposed interventions as the Act makes statements about an individual 'lacking' rather than having capacity for the decision that is being made, therefore mapping more closely onto Banner's 'thin' rather than 'thick' conceptualisation of mental capacity. Capacity decisions for 'requests' including for assisted suicide appear to have their origins more in a 'thick' conceptualisation of capacity which as Banner suggests may not be fully served by the current legal structures. In addition the Act stipulates some explicit exclusions to its use (in part 3, section 62), one of which is in the operation of the Suicide Act 1961 [43] (assisting suicide); therefore the proposition of using the Mental Capacity Act for capacity assessment for patients requesting assisted suicide potentially presents a legal as well as a clinical problem.

The tension between differing conceptualisations of mental capacity presents difficulties for policy makers,

lawyers and clinicians. If, as the Commission recommends, we consider a model of capacity assessment that seems implicitly to presume non capacity and place the burden of proof on determining that capacity is present rather than absent, then it is difficult to see how the procedures set out in the Mental Capacity Act 2005 can be applicable. The question is raised as to whether it is Mental Capacity Act 'mental capacity' or rather a broader set of faculties that the Commission (and subsequent Bill) envisages, which have an inherent value ladenness that may render the process more subjective, and arguably provide a less reliable safeguard in the process.

The experts presenting evidence to the Commission on Assisted Dying were inconsistent in their conceptualisations of mental capacity as it relates to assisted suicide. Before mental capacity can be placed so centrally as a safeguard in the process, discussion needs to take place about what exactly is meant by the term 'mental capacity' in the new Assisted Dying Bill. Only then can decisions be made as to whether it meets the need for which it has been identified and whether current legal frameworks are able to support clinicians in determining capacity for this group.

Competing interests

All authors declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; MH and AP presented evidence to the Commission on Assisted Dying and advised caution in considering mental capacity as a safeguard in assisted dying legislation, MH was on the Royal College of Psychiatrists working group on Assisted Dying, and during a consultation run by the College, voiced concern about a change in the law based on his experience of caring for people requesting assisted dying.

Authors' contributions

AP, TW and MH devised and planned the study. AP and RM planned and performed data analysis supervised by TW and MH. AP drafted the manuscript and all authors contributed to the submitted version. AP is guarantor. All authors read and approved the final manuscript.

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